In compliance with the
Canadian Privacy Legislation
some supporting forms
may have been removed from
this dissertation.

While these forms may be included
in the document page count,
their removal does not represent
any loss of content from the dissertation.

University of Alberta

The Lived Experience of Obsessive Compulsive Disorder

by

Mary Tunnicliffe Haase

©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Faculty of Nursing

Edmonton, Alberta

Fall 2003

National Library of Canada
Acquisitions and Bibliographic Services
395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale du Canada
Acquisisitons et services bibliographiques
395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 0-612-87983-6
Our file Notre référence
ISBN: 0-612-87983-6

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou aturement reproduits sans son autorisation.

Canada

University of Alberta

Library Release Form

Name of Author:	Mary Tunnicliffe Haase
Title of Thesis:	**The Lived Experience of Obsessive Compulsive Disorder**
Degree:	Doctor of Philosophy
Year This Degree Granted:	2003

Permission is hereby granted to the University of Alberta Library to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as herein before provided, neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.

Sept 30 '03

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **The Lived Experience of Obsessive Compulsive Disorder** submitted by Mary Tunnicliffe Haase in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Olive Yonge, RN, PhD, Co-Supervisor

Jeanette Boman, RN, PhD, Co-Supervisor

Marjorie Anderson, RN, PhD

Max van Manen ~~PhD~~

Lorne Warneke, BSc, M.D., L..M.C.C., F.R.C.P.(C)

Sept 16 '03

Sonia Acorn, RN, PhD, External Examiner

Dedication

To my husband Ken, my best friend and greatest support, and to our children Shelagh, Nicole (Jeremy), Matthew, and Kathleen.

To my sister Janet.

To my parents Kathleen and Cyril Tunnicliffe, my brother John, and my friend Yvonne, all of whom died during the time of my journey to achieving a PhD in Nursing.

To all of my participants who live every day with obsessions and compulsions.

Abstract

The purpose of this hermeneutic phenomenological study is to offer an interpretation of the lived experience of obsessive compulsive disorder (OCD). Fourteen participants shared their stories of living with OCD and eleven of the participants made drawings depicting their OCD. Their stories and drawings invite readers into the lifeworld of OCD and provide a deep understanding of the experience.

Anecdotes are artificially divided among the existentials of relationality, corporeality, spatiality, and temporality. I say artificially because in reality each of the existentials interacts with the others. Anecdotes of ordinary behaviour are set side by side OCD anecdotes to show the nature or the appearance of OCD by comparing it with ordinary human experience. Having shown the differences between ordinary and OCD behaviour I show the sameness of ordinary experience and OCD experience. In showing the sameness I put OCD side by side behaviours that are sort of like OCD, but not OCD. In doing so, OCD becomes more understandable.

What emerged from this writing were possible interpretations of the lived experience of OCD. It is hoped that an understanding of OCD will lead to more thoughtful practice. Questions that are not answered in the text remain; to be pondered and researched in future projects. This text has opened the discussion on the lived experience of OCD, but has not offered definitive answers. For now, it is not "just right".

Acknowledgements

I am forever grateful to the 14 participants in my study who shared their stories with such honesty. I thank you for entrusting me with your stories and allowing me to give you a voice. I am hopeful that your stories will help others with OCD and give health care professionals new insights into OCD. Thank you.

My journey to a PhD in Nursing has been a long one. I acknowledge Claire Kibbler and Julie Lazaruk for being the first to encourage me to continue my nursing education. Thank you to my friends Barb, Claude, the two Joans, Les, and Colin, who have offered me support and lots of laughter during my journey. I thank you for caring about me. Sharon, Neil, Ed, Shelley, Ann, Pat, Gerry, Laurene, Anne, Kathleen, Gregg, Bev, Rick, Stan, Marlene, Liz, Louise, Denise, Dan, and Dianne, I thank you for always being there for me even when I was not always available to you. I will always remember your generosity of friendship. To my colleague and fellow phenomenologist Patricia, I thank you for listening to all of my many drafts and for sharing your valuable insights into my writing. I could not have done it without you. I would also like to acknowledge my colleagues Ann, Bev, Trisha, and Lisa for pushing my thinking to new levels and for caring. Thank you.

To my sister Janet, I thank you for your unfailing support. Your words of encouragement kept me going when I thought I could do no more. You knew I could do it; you just wondered when. Thank you.

To my brother David and his wife Karen, I thank you for being my twin and always being with me in spirit. Thank you.

To my committee members, I am indebted to each of you for your generosity of time, energy, and wisdom. Olive, I thank you for the faith and hope you instilled in me, not only about my ability to complete this dissertation, but in life as well. You will always have a special place in my heart. Jeanette, I thank you for giving me courage. You gently challenged my thinking, but at the same time showed me the way. Marjorie, I thank you for always having time to speak with me and for questioning my qualitative mind. Your questions stimulated my thinking and made me a better researcher. Lorne, I thank you for supporting my research and for caring about me. Max, I thank you for your phenomenological expertise and your great sense of wonder. You have taught me how to be more mindful in my life. I have been privileged in knowing each of you. Thank you.

I would like to acknowledge the financial support I received from the University of Alberta, Faculty of Nursing, Province of Alberta, and the Alberta Association of Registered Nurses.

Finally, I would like to thank Elaine and Winnie for being so patient with me during my graduate student years. I really did appreciate all of your help and kind words. Thank you.

Table of Contents

Page

CHAPTER I: INTRODUCTION 1

Purpose of the Inquiry 2

CHAPTER II: REVIEW OF THE LITERATURE: OBSESSIVE COMPULSIVE DISORDER 29

General Description of Obsessive Compulsive Disorder 29

History of Obsessive Compulsive Disorder 31

Presentation of Obsessive Compulsive Disorder 34

Common Obsessions and Compulsions 36

Course of Obsessive Compulsive Disorder 37

Patterns of Remission and Relapse 39

Switching of Obsessions and Compulsions 40

Prevalence of Obsessive Compulsive Disorder 41

Comorbidity with Obsessive Compulsive Disorder 42

Theories of Causation and Treatment 43

Injury, Illness, or Infection 44

Biological Model 45

Cognitive Model 47

Behavioural Model 50

Combining Biological, Cognitive, and Behavioural Therapies 54

Experience of Obsessive Compulsive Disorder 56

Conclusion of the Review of the Literature 57

Page

The Research Question 58

CHAPTER III: THE METHOD: HERMENEUTIC PHENOMENOLOGY 60

Turning with Commitment 61

Experience as Lived 62

Reflecting on Essential Themes 65

Act of Writing and Rewriting 66

Continuous and Strong Orientation 67

Considering Parts and Whole 68

Participants in the Inquiry 69

Ethical Considerations 70

CHAPTER IV: HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF RELATIONALITY? 77

Wanting to, Not Wanting to, Having to 77

In the Grocery Lineup 80

Vigilant Watch 83

Do You Love Me? 84

The Voices 86

Gossiping or Must Tell? 91

CHAPTER V: SEEING THE SAMENESS, IN THE DIFFERENCES OF ORDINARY RELATION AND OCD RELATION 95

Being or Feeling Responsible? 95

Desire or Want? 97

Page

Part of Me and Part of Me 99

Resisting the Must 103

CHAPTER VI: HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF CORPOREALITY? 106

In My Head 106

Making a Sandwich 108

Anxiety in Me 109

Missing Parts 111

What if I Have a Disease? 113

Bump in the Road 115

Building Up and Letting Go 117

Scuffing my Shoes 120

Cleaning up the Kitchen 121

Caught in a Vice 122

Cutting My Fingers Off 123

A Family Christmas 124

Sleeping 125

CHAPTER VII: SEEING THE SAMENESS, IN THE DIFFERENCES OF ORDINARY CORPOREALITY AND OCD CORPOREALITY 128

Feeling Anxious 128

Stuck in my Thoughts 132

Feeling Good 133

Page

Ritual or Habit? 134

Mental Anguish of OCD Pain 137

Rest My Body Perchance to Dream 140

CHAPTER VIII: HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF TIME? 143

List Making 144

Good Night 145

The First Time 147

Picking 151

Laundry Day 152

Starting the Day 155

Finding What I Want 157

Feeling Lumps 158

CHAPTER IX: SEEING THE SAMENESS IN THE DIFFERENCES OF ORDINARY TEMPORALITY AND OCD TEMPORALITY 161

Comfort 161

Knowing 163

Choice 165

Lost 166

Touch 167

Page

CHAPTER X: HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF SPACE? 169

Checking Over and Over 169

Holding On 173

Driving the Car 175

Seeing is Not Believing 178

Getting Clean 180

CHAPTER XI: SEEING THE SAMENESS, IN THE DIFFERENCES OF ORDINARY EXPERIENCE OF SPATIALITY AND OCD EXPERIENCE OF SPATIALITY 183

Just Right 183

Being in Control or Being Controlled 185

Trust 187

Ordinary 188

Finding My Space 190

CHAPTER XII: CONCLUDING COMMENTS 193

REFERENCES 196

APPENDIX A: DSM IV DIAGNOSTIC CRITERIA 220

APPENDIX B: RECRUITMENT ANNOUNCEMENT 222

APPENDIX C: INFORMATION LETTER 224

APPENDIX D: INFORMED CONSENT 227

APPENDIX E: RESOURCES 229

Page

APPENDIX F: PERSONNEL 231

APPENDIX G: DISSEMINATION PLAN 233

CHAPTER I

INTRODUCTION

> STANDING, I always have to be standing when I get dressed because standing has a D, A, and N in it, for my husband's name. I take four steps to the dresser, reach out with my right hand, and open the drawer. I pull out my underwear first, the fourth pair down; but sometimes the fourth pair isn't just right, and I have to pick according to colours containing D, A, or N. Red is the best, followed by orange, black, cream, green, and then brown. I don't know beforehand versus colour or number; it is whatever my brain decides at the time. I put my underwear on, stepping into them with my right leg first, counting one, two, three, and four as I pull them up. I end with my left leg going in, as my left side is my OCD side and I must always end everything with my left side. If this is not done correctly, if I lose my balance, or if it doesn't feel just right, I have to repeat the same actions in multiples of four (four, eight, twelve, sixteen) until my brain says it is done correctly. It has taken me forty minutes to put on my underwear, but I wouldn't take the chance of not doing these rituals because the unknown consequences seem to be horrific in my mind. Obsessions and rituals rule my life; I am never free of doubt. It is like looking normal on the outside and feeling crazy on the inside. (Leah)

Leah suffers from a mental disorder known as obsessive compulsive disorder (OCD). This anecdote was gathered during a conversation I had with her. I will explore OCD in more detail during my research inquiry and outline current thinking in the following review of the literature.

Purpose of the Inquiry

The purpose of this hermeneutic phenomenological inquiry is to explore and gain a deeper understanding of the lived experience of OCD. My goal is to turn the lived experience of OCD into a text that the readers and participants will not only understand, but also claim as their own. I hope that nurses and other health care professionals gain a richer understanding of OCD as well as learn how to approach an individual with OCD in the moment in a tactful and thoughtful manner. I also hope that this inquiry will advance knowledge about living with a chronic mental condition and advance health knowledge because it is relevant to those with OCD and their families.

The individuals you are about to meet in this study all have the lived experience of OCD. To enter into their experience is challenging. I invite you into their experience by first sharing their drawings of OCD.

Mark D. Twain and Sunflower decided not to do the drawing, and Lisa shared a picture her daughter Emma drew of her. Eleven out of fourteen participants did do a drawing.

The picture that Jane drew is entitled "Spinning in Rigidity." The following is her description of her drawing.

> When I am obsessing I have this feeling of being enclosed, enclosed in that dark spiral. The obsessing sneaks up on me, and if I don't keep up the battle against the OCD, I will be engulfed. I have to work at it all the time. I am encapsulated within the black. The central black circular area is what I would call a wheel spinning on my thoughts, going around and around. My wheels spinning take me deeper and deeper. I get embedded in the spinning. I am sometimes able to move into the red, but I still get drawn

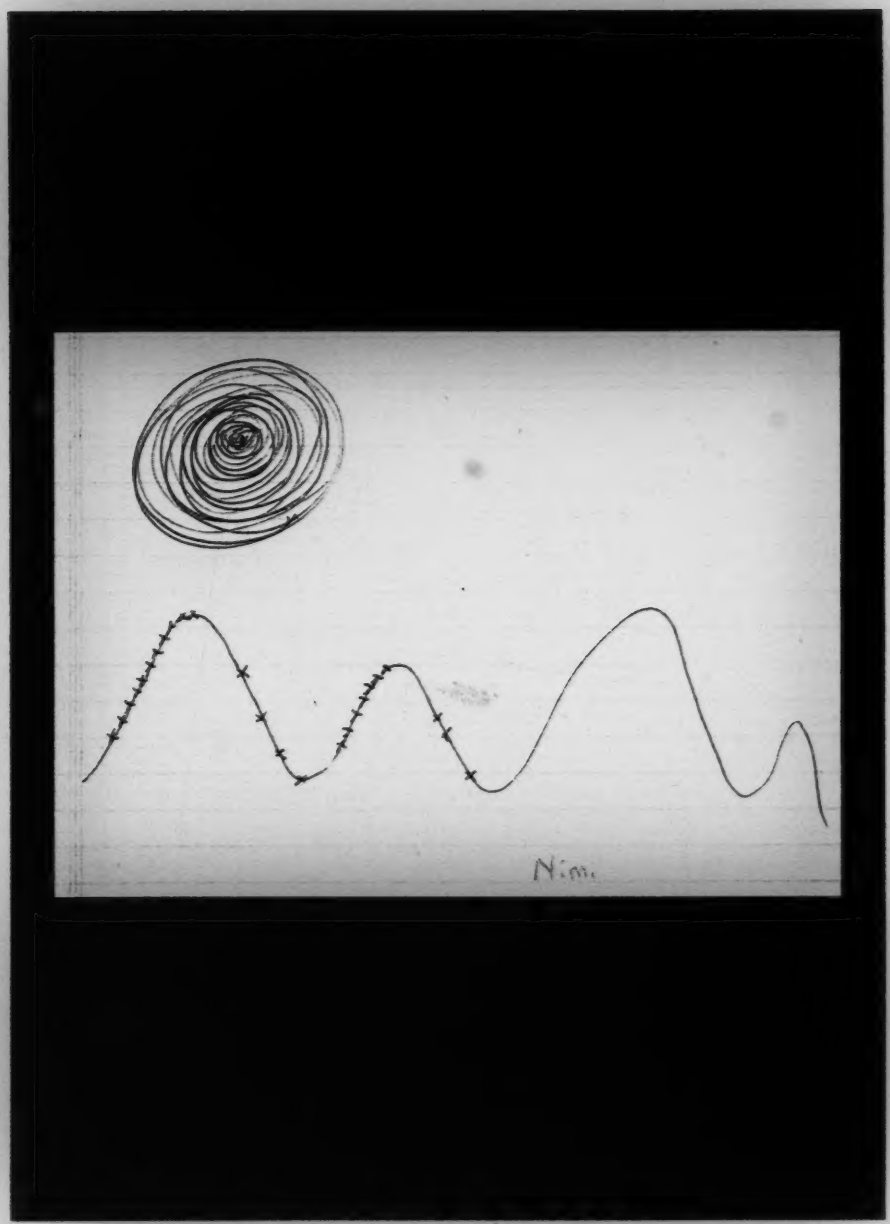
back into the black circles. I struggle. There is an argument in my head as I move back and forth between the black and the red. When I move into the red I am intellectualizing and the OCD is actually getting worse. Each red line represents another attempt to go out and rationalize the OCD. So when I do escape from the OCD, it is always from the black circles. If I were to draw getting out of it, it would be la line straight out. It would be perfectly straight. The black and the red actually depict a big struggle that goes on within my mind. We'll try again and again to intellectualize, but come back to the obsessing and keep repeating endlessly. That is why I've got it circled that way, because it is kind of an endless thing. The curves in the red show where I am trying to make sense of the obsession. Often I do not succeed though. It is spinning in rigidity, like being trapped definitely. It is like I have to do the rituals, yet I don't want to do them. That is right, exactly. That is where I get the argument in my mind: wanting to get out of the ritual but then feeling pulled back in again, again, again. That is part of what it is, like an argument in my head, but it is more of a struggle to free myself from the obsessing, and then it pulls me back. That describes it. In the beginning of my OCD I could not escape from its grips. I was in Hell. I was immobilized completely. Now I get caught in the spinning for a while, but I can usually get myself out of it. Sometimes it takes longer though. I have been so stuck that I'm not aware of hope, and hope is what I need in order to escape.

Gertrude drew a picture of herself. I find it interesting that she drew only her head, because many of the participants told me that OCD was only in their head.

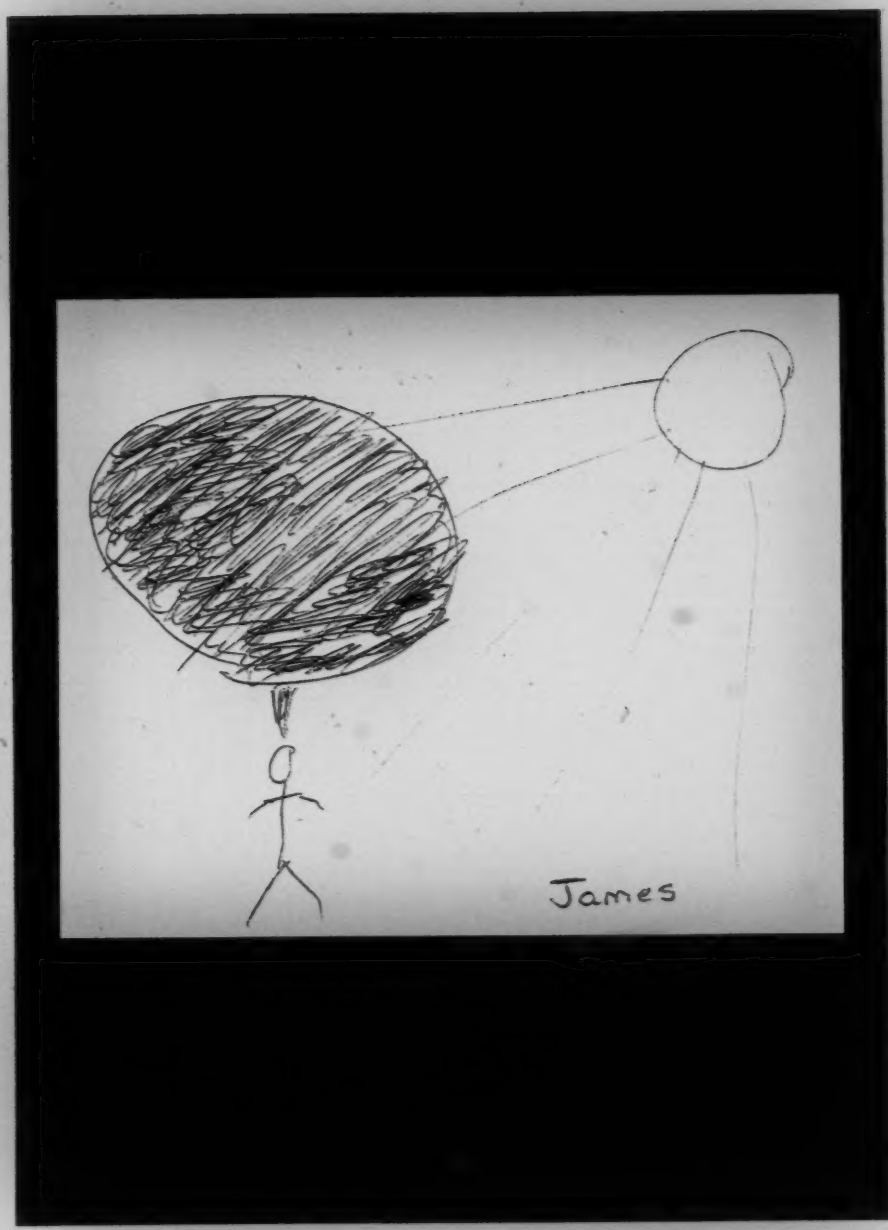
> The straw hair shows my frustration with OCD. My eyes are wide open so they don't miss anything. I am always on guard. My nose is a bit long because it is like a witch's nose. OCD is mean. It doesn't want to let go. It is wicked. Keeps beating on you. The necklace is because OCD wants to look normal, accepted. I want to look nice too. I drew my mouth bigger because it is always open. Always wants to beat up on me, torturing me. The line drawn across my throat was an accident. I did not mean to draw it there. I don't think there is any significance to that line. The mark on my ear is an earring.

*Draw OCD Picture
Gertrude

Nimi's drawing shows her cycle of anxiety. It starts out as a pinpoint and rapidly gets bigger and bigger as the anxiety grows and grows. When she reflects on the obsessive thought, the anxiety gets stronger. Soon it overwhelms her, and she is compelled to carry out the needed ritual. Once the ritual is performed correctly, the cycle reverses. The anxiety lessens and finally becomes a pinpoint. The waving line at the bottom shows how the OCD comes in waves. The xxxs represent Nimi's feeling and measuring of her lumps. The more xxxs, the more intense the checking. When the waves are high the OCD is at its worst. Nimi is not certain whether OCD drives the anxiety or anxiety drives the OCD. She suspects that if the anxiety was driving the OCD, the line depicting her OCD would not be wavy but, rather, straight and diagonal. The line would represent a steadily increasing anxiety.


Nim.

My (James) picture of OCD appears to be quite simple, but it actually has a very deep meaning. I am that little figure. I feel like a stickman. I feel like I have lost so much of myself to OCD. The cloud over my head represents the time and energy I have spent listening to the obsessive thoughts and feeling the fear they evoke within me. The cloud is like a blackness that talks to me, communicates with me. The hours I have spent checking, decontaminating, and washing are also in the cloud. I am always walking around with that black cloud lurking over me. The sun is when I am able to break out of the OCD. The rays of the sun are hope.


James

When you look at the picture I (Machiavelli) have drawn, you will see the complexity of my obsessions and compulsions. I will try to go through it a little at a time. The clock shows my obsession with time and scheduling. I write out a daily, weekly, and monthly schedule. Of course these always change, so I have to write them out again and again. It is all very time consuming. The clock is very precisely divided into the hours.

The words around the left side and at the bottom represent the importance of those things to me. I could not survive without these things. I need all of them to do my work. I need them to be able to organise. I am very preoccupied with all of these things.

The lopsided bubble with the stick figure inside represents me being trapped inside the bubble of OCD. I am still able to reach out to the rest of the world, but the world can't reach me. The bubble is pushed out, but it will never break open. I will always be confined there. I want to be able to smell the roses, but OCD does not let me out to be free. The formula in the bubble is my attempt to get organized. I try and try, but never succeed.

The math formulas show my wish to acquire knowledge. The math sequence is my search for the perfect number. It approaches the golden number but never reaches it. I keep working with the sequence all the same. The other sequences and series of numbers in the drawing are my favourite.

The double-ended arrow shows my ongoing attempts to get organized. I believe that if I can find order in my life, I will have peace. The top arrow, that points to disorder-organise-order-simplify-peace, represents my wish for order, but the lower sequence is what really happens. I spend so much time organising and organising more that the organising never stops. I never reach peace. My OCD interferes in my search for peace.

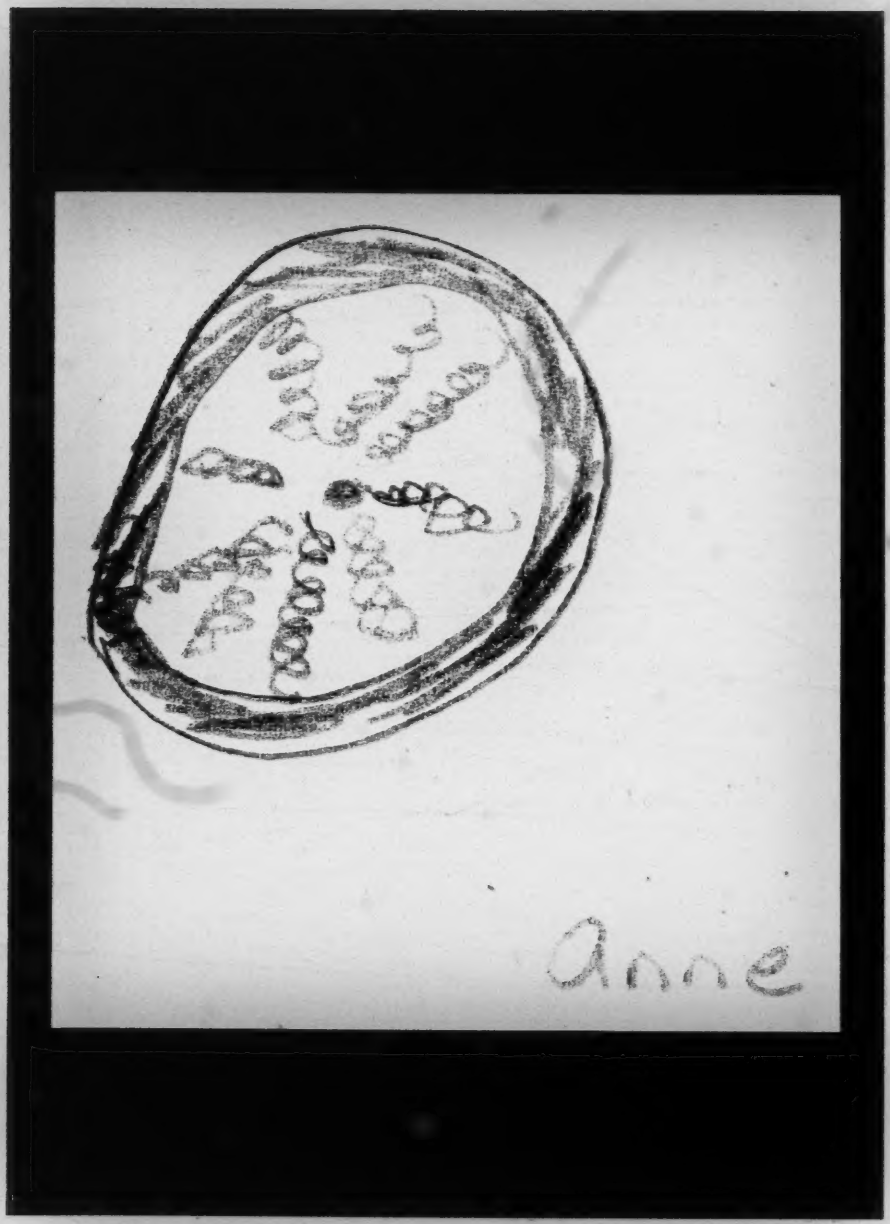
The funny little face with the series of small and large circles leading to the sun represents the story of my life. I am the little face, and

the sun is the light at the end of the tunnel. The little circles in between show how OCD has waxed and waned over my lifetime. The smaller circles show times when OCD was less severe and less interfering. The larger circles show the times when I was overwhelmed by OCD. You can see that most of my life has been a struggle. I have lived with OCD for my lifetime.

The little stick man with the sad face is me. I have chains on my arms and one leg. The chains are the obsessions and compulsions that jail me. OCD does not have a complete hold on me though because I still have one leg that is free. The arrow points to me flying away from OCD. It shows me being released.

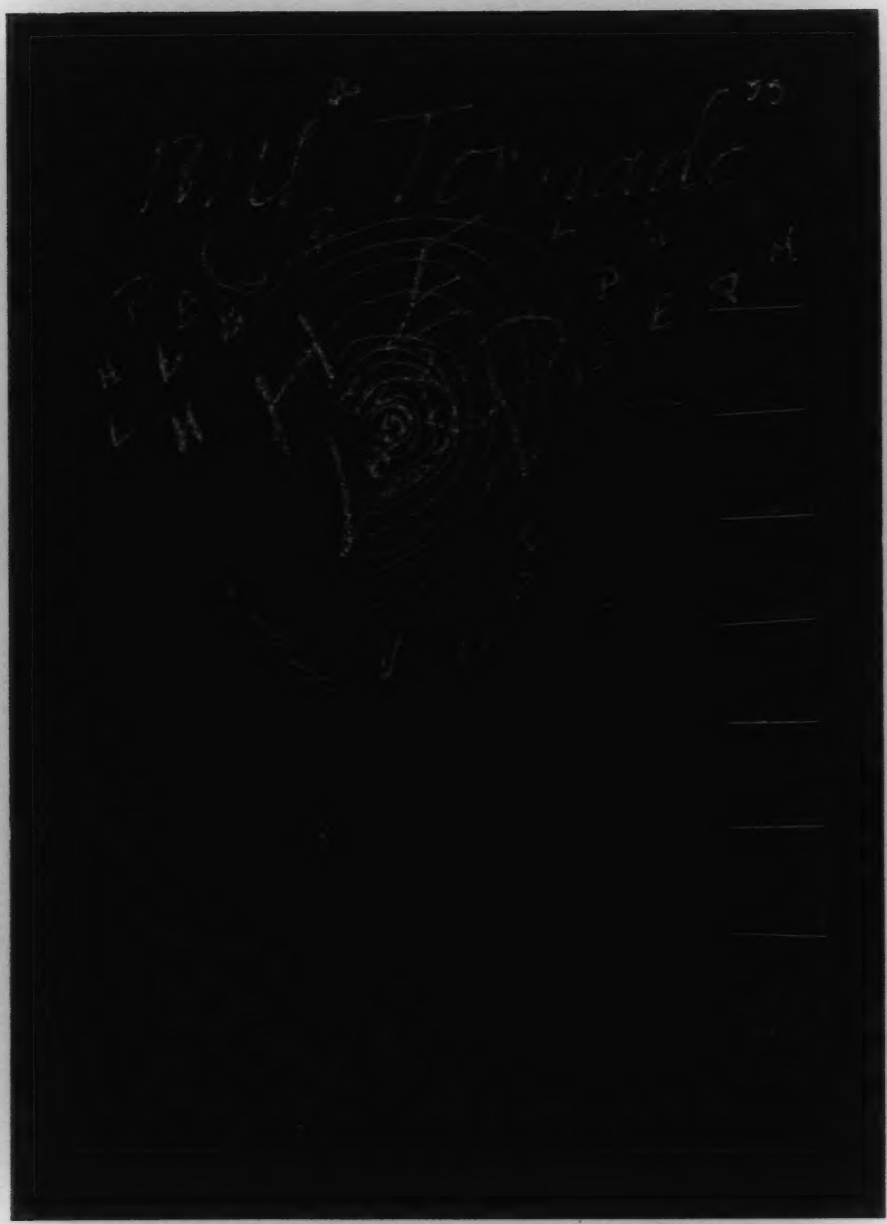
[ERASER]
[calender]
[pen/paper]
[clock]
[Weights and measures]
$F_{n+2} = F_{n-1} + F_{n-2}$
0, 1, 1, 2, 3, 5, 8, 13, 21...
$1 + \Phi = 1/\Phi$
"golden recorder"
$f - e + v = 2$
$6 - 12 + 8 = 2$
$t_{n+2} = a + (n+1)d$
2, 4, 6, 8, 10...
"disorder → organize"
"disorder → organize"

Anne's picture of her OCD is interesting. She describes it as being a circular black box. She is the circle and the coils are balls of anxiety that spin around and hit her constantly. The dot in the middle of the coils is the OCD. It is the OCD that sends the balls spinning inside her. The black box is like those found on aeroplanes that record all the important information. The box is not visible in the drawing. Anne is afraid that if the box were visible I would not believe that she had OCD. She is afraid that I would just think she is crazy.


Anne

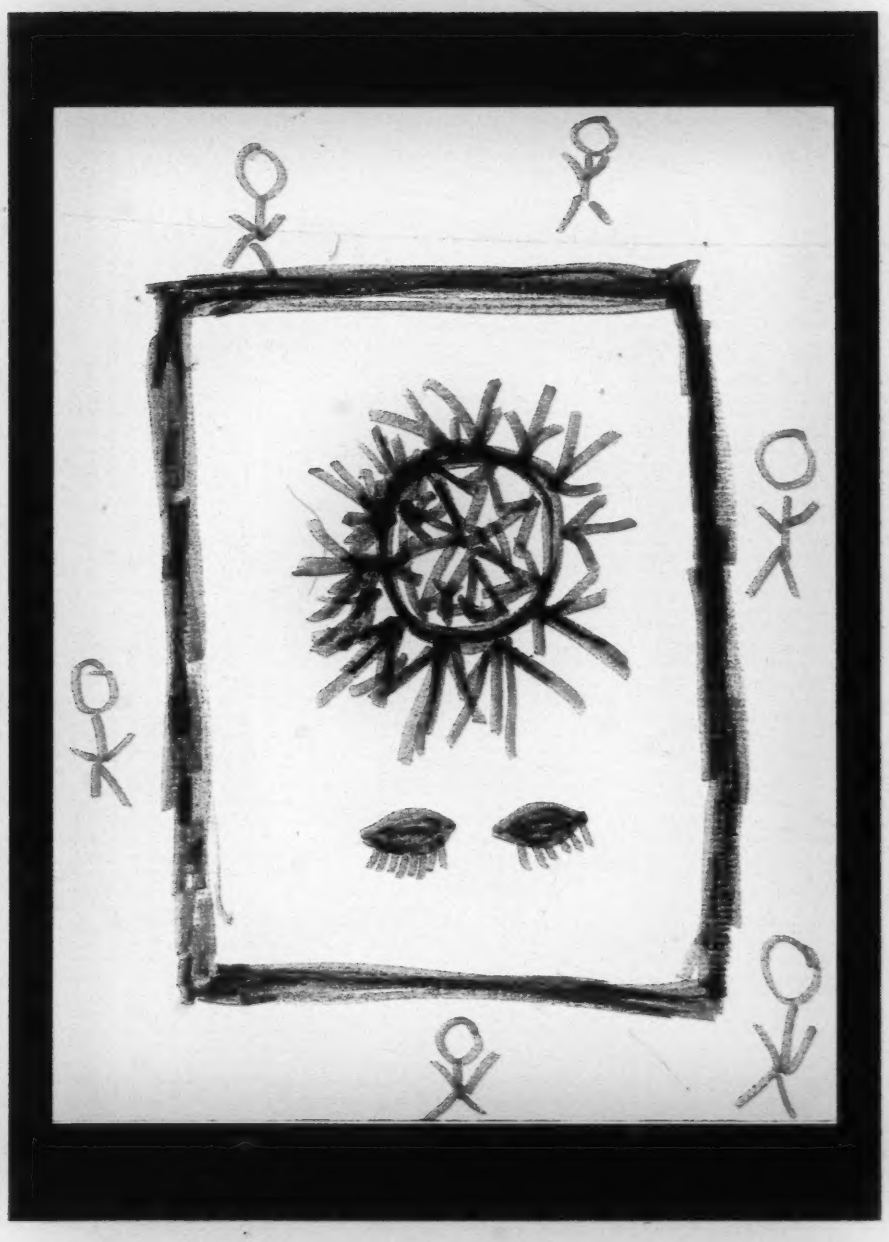
Christy's drawing shows the desperation she feels when in the moment of her obsessions and rituals.

> I call my drawing "My Tornado." OCD is like a tornado that sucks me up and takes me away from myself. It takes all of my control away. I can't fight something as strong as a tornado. The spiral is the tornado. I get pulled in, and all I can do is call for help. All the green letters spell "Help me please. Please help me." Over and over. The call for help is just like the obsessions and rituals. I call over and over again, and no one comes. I do the rituals over and over again, and I get no relief. I get caught in doing the rituals, and it is hard to get out. Sometimes I have to scream and try and shock myself into reality. I try to understand why the OCD always sucks me up. I get caught in a cycle of fear and anxiety. It is vicious. I don't know if I am coming or going. I don't know what I am doing half the time. I am just spinning around and around. The large V shapes each have a meaning. The lowest one shows how the rituals kind of sneak up on me. By the time I reach the second V, I am still able to ask for help. The third V is my last chance to gain control over the ritual before I am sucked into doing the ritual over and over. The word *tornado* on the right side is in gold and black for a reason. The fancy gold shows how cunning OCD can be. You think it is going to help you if you do the ritual, but soon you are trapped in the blackness of the OCD tornado.

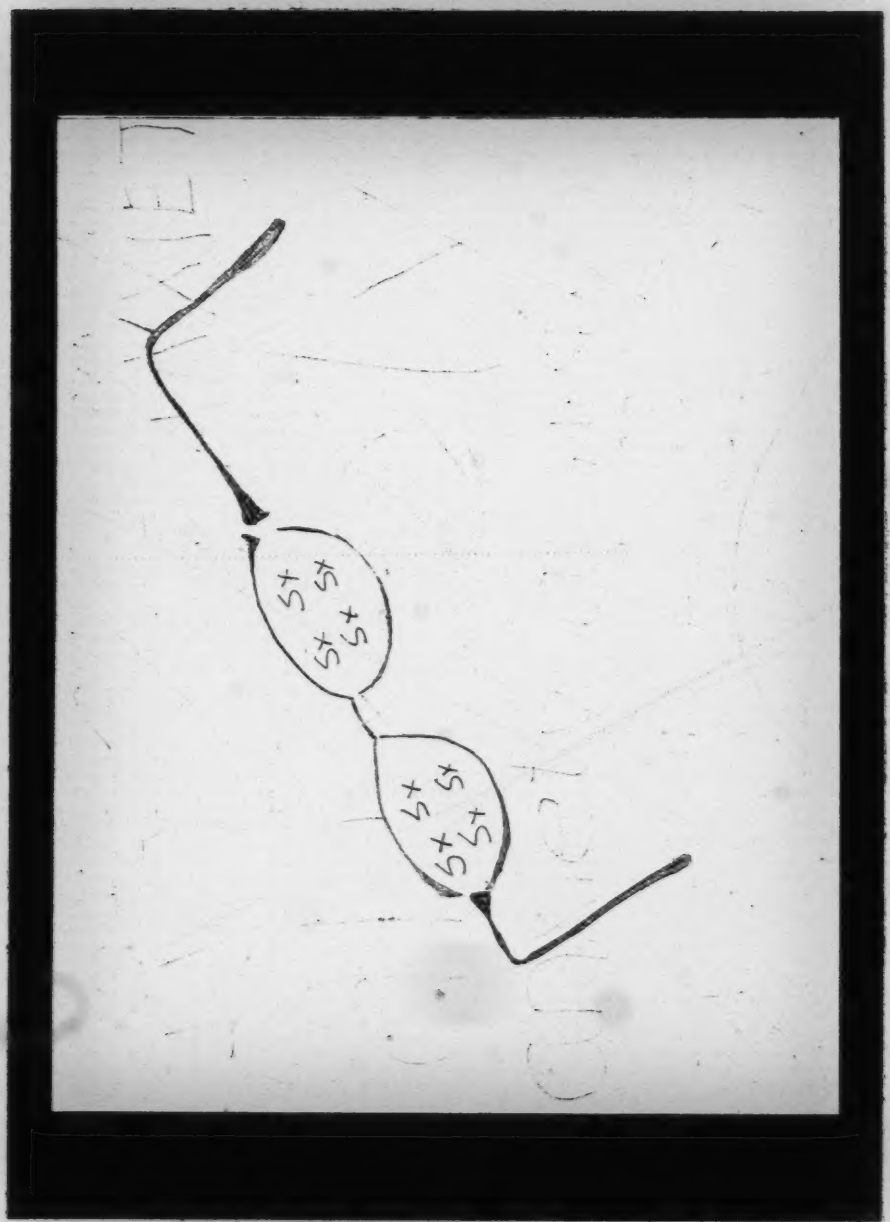


Linda's picture is in green, but she told me that it should be in black and red. The black would depict the darkness of OCD and the red would depict the exploding force of the OCD.

> The box represents the isolation OCD brings to my life. The people on the outside of the box are other people that I cannot let into my life because of the obsessions and compulsion. Having OCD has forced me into a limited life. The circle with all the arrows bombarding it represents my brain pressure moving in and out as the obsessive thoughts intrude on my thoughts. My eyes are closed in an attempt to shut everything out. I want the obsessive thoughts to stop.

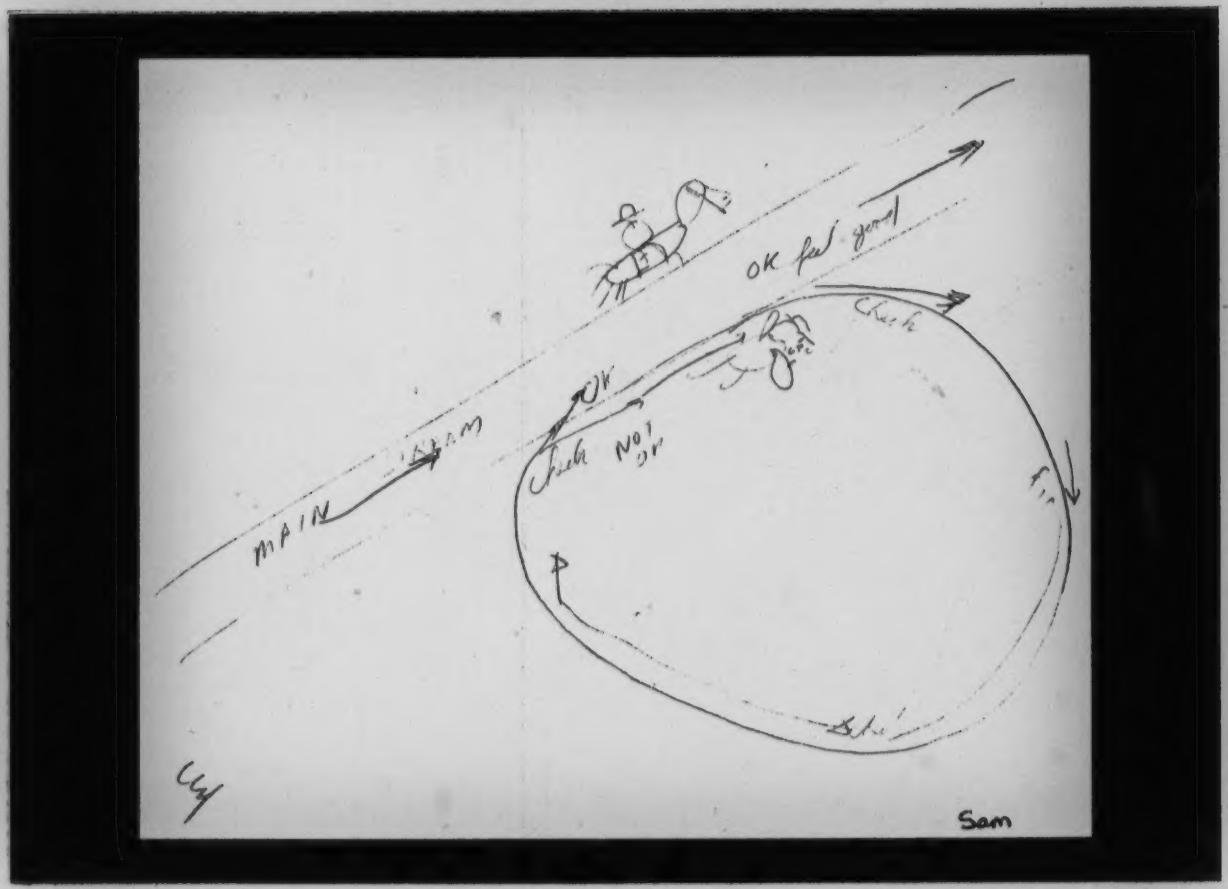


My (Roxanne) picture represents a period in my life when I had a fear of developing schizophrenia. All I could see was schizophrenia. Everywhere I looked I recognised symptoms and I became concerned I might have the symptom. I was constantly scanning my body and my thoughts. I had this dreaded fear, and I did not know what to do. It was quite some time later that I finally recognised that I was continually anxious. It was like everything I did and everything I thought was through this veil of anxiety. The anxiety was not visible to me for a long time. Once I identified and named it as anxiety, I was better able to gain control. I was finally able to recognise intrusive thoughts for what they were. I no longer had to perform rituals to protect Richard and myself. OCD is still in my life, but I am better able to manage it now.


5x
5x
5x
5x
5x
5x
5x
5x

Lisa compulsively picks at her skin. If she does not have a spot to pick, she pokes and scratches at her skin until there is a spot. She feels pulled to the mirror. She does not want to pick her skin and has made many attempts to stop, but with little success. Lisa recalls standing at the mirror while her little girl called out to her to come and see her printing homework. She told Emma that she would just be a minute. Emma called back, "No you won't. You will be an hour. I know." Lisa felt ashamed. She honestly thought that her children did not notice her picking. Later that week Emma brought home a drawing of her mother that she had done at school. Lisa was mortified. She tried to hide her picking, but there it was for all to see. Red spots all over her face.

My (Sam) need to help others has got me into trouble a number of times. If I see someone broken down on the freeway, I have to stop and help him or her out. It doesn't matter that I put my life at risk by crossing over four lanes of a busy freeway. My drawing shows how the need to help draws me in. Once I start to help, I cannot stop. That is me riding on the horse. I picture myself as a knight in shining armour riding out to aid those in distress if I can. I am travelling along, and I see someone collapsed on the side of the road, like the figure I have drawn; I have to stop. It is physically impossible for me to ignore their distress. I get caught in a cycle of checking the situation out over and over. One quick check is never good enough; I have to ensure it is complete. Once the situation is under control, I can climb back on my horse and ride away, feeling good about what I have done. But the good feeling does not last for long. Pretty soon I am looking for another damsel in distress.


OK for ground
MAIN
Sam

My (Leah) picture is in black and white on purpose. I want to show how OCD is black and white; there are no grey zones. Rituals must always be completed correctly. I can never take the risk of not doing something as it should be done. The consequences are too horrific to take the chance. I always do my rituals correctly. If I am trying to brush my teeth correctly and one of the children interrupts, I am able to stop and go and help them with whatever it is they want, but I must return to finish the ritual of brushing my teeth. It doesn't matter if it is two hours later; I must do it.

Everything I do in my life is to the count of four. Four is my lucky number. The clock around my head has only the numbers one to four because they are the only numbers that matter. I could never do something only three times; it has to be four times. When I put on my mascara it is always to the count of four. If I don't do it correctly, like if I miscount or it doesn't feel just right, I have to start over. You can imagine that some days I am wearing a heavy dose of mascara.

The split in my head is not a lightening bolt, but rather a depiction of my divided mind. Part of my mind is very rational and the other part is basically irrational. I mean, have you ever heard of a woman who can't spend money? Well, that would be me. I can't spend money because of the numbers and letters on the bills. The number four is important, and so are the letters D, A, and N for my husband's name Dan. I need to know

where the money is going in case I have to get it back some day. I never know when I might need that very bill. Crazy, hey?

The tear coming out of my eye is a depiction of the frustration I feel. I look so normal on the outside, but I feel crazy on the inside. People without OCD have no comprehension of the frustration, anxiety, and fear. It is beyond words.

The rope around my neck with the two little women pulling on either end is my good angel and bad angel. They are both really me. Because of the OCD I am constantly in a battle with myself. Both angels talk to me. The bad angel is constantly telling me to do the rituals. The good angel is always trying to encourage me to see the sense in the situation. The bad angel will tell me to pick up the pieces of garbage on the airport floor, but the good angel will tell me to leave the garbage. Who heard of picking up garbage off the floor to ensure good luck? I always listen to the bad angel. The good angel can never give me enough assurance that some catastrophe will not happen. I never win the tug of war.

CHAPTER II

REVIEW OF THE LITERATURE: OBSESSIVE COMPULSIVE DISORDER

For the review of the recent OCD literature, a computer search using the databases Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, Psyc INFO, and Educational Resources Information Centre (ERIC) was conducted. A hand search uncovered a few more articles. In total, hundreds of articles were found, but only a few gave either a qualitative or a nursing perspective of OCD. The majority of the articles focused on empirical studies, etiology, epidemiology, prevalence, assessment, and treatment of the disorder. Seminal articles and books were identified, such as Meyer (1966), who first implemented a treatment that utilized both exposure and response prevention; Beck (1976), who developed cognitive therapy; and Flament et al. (1988), who conducted the first epidemiological study of OCD.

General Description of Obsessive Compulsive Disorder

OCD is a mental disorder characterized by obsessions and compulsions (American Psychiatric Association [APA], 1994). See Appendix A for a detailed description of obsessions and compulsions. OCD is one of the most enigmatic of the psychiatric conditions. Individuals experience intrusive, inappropriate thoughts or images that cause distress and anxiety. They are aware that these ideas make no sense and are foreign to their mind, but they cannot simply dismiss them (Spitzer & Sigmund, 1997).

The original meanings of the term *obsess* include "to hunt, trouble, harass, from the Latin *obsidere,* to besiege" (Klein, 1971, p. 507). The person is literally harassed by recurrent, persistent, and unwanted thoughts; and troubled by impulses, feelings, or images that are experienced as intrusive and senseless. These thoughts, impulses, feelings, or images are not simply excessive worries about real-life problems; they are also brought on by doubt and fear of harm coming to one's loved one, of not doing something "just right," of losing something, or of contamination. Along with unwanted thoughts, images, or impulses, the person experiences a mounting anxiety. It is thought that the compulsions are carried out in an attempt to lessen the anxiety brought on by the obsession.

The term *compulsion* comes to English, via French, from the Late Latin "*compulsio*: to compel" (Thompson, 1995, p. 274). Compulsions or rituals are repetitive, ritualized behaviours or mental acts that an individual feels compelled to carry out, even if he or she does not want to do so. A person may feel compelled to enter and reenter a doorway until it is done "just right." Only then can he or she stop the obsessive fear of harm coming to a loved one. Completion of the compulsion tends to bring temporary relief of the anxiety, but the obsession quickly returns, anxiety mounts, and the compulsions begin anew.

OCD is often chronic and disabling, affecting the life of the person with OCD, families, and friends. Many individuals with OCD feel isolated, alone, and misunderstood by family and friends (Black & Blum, 1992). Obsessions and compulsions are time consuming, cause significant distress, and impact on an

individual's social life and career (Hollander, Kwon, et al., 1996). Compared to individuals without OCD, individuals with OCD are less likely to marry, are at greater risk for divorce, and tend to isolate themselves (Rapoport & Baer, 1993; Zetin & Kramer, 1992). In a 410-item survey which, in part, assessed the effects of OCD on the lives of people with the disorder, 2,600 questionnaires were sent out, with a 27% response rate (n=701) (Hollander, Kwon, et al., 1996; Hollander et al., 1995). The researchers found that OCD symptoms caused significant distress and interfered in the lives of individuals with the disorder. An overwhelming 88% had marked interference with social and occupational functioning. Between 60% and 70% had *much* or *very much* interference in their ability to continue with schoolwork, employment, socialization, and relationships with family and friends. Steketee, Grayson, and Foa (1985) found that in their sample of 75 individuals with OCD, 37% never married, and 25% continued to live in the family home. OCD can affect every aspect of an individual's life.

History of Obsessive Compulsive Disorder

Prior to the 19th century, people with OCD were often considered to be possessed by the devil or evil spirits, and initial treatments focused on exorcism and torture (Hurley, Saxena, Rauch, Hoehn-Saric, & Taber, 2002; Jenike, Baer, & Minichiello, 1998; Zohar, Insel, & Rasmussen, 1991). Accounts differ as to when OCD was first described in the psychiatric literature. Warneke (1993) reported that the German neurologist Carl Westphahl described OCD in the late 1800s, whereas Janet was the first to describe the disorder in 1903, according to Hanna (1995). Rachman and Hodgson (1980) identified Esquirol in 1838 as the

first to describe OCD. Despite the conflict of when OCD was first described, OCD has a very interesting history.

The word *obsession* was first used in France late in the 19th century. Before this time the nature of OCD invoked descriptions such as *monomania* and *folie lucide* (Spitzer & Sigmund, 1997). Westphahl (1878) (as cited in Spritzer & Sigmund) provided health professionals with the classic description of obsessions:

> Obsessions are ideas that enter into the foreground of consciousness against the person's will. They cannot be dismissed, obstruct the normal mental processes, and they are regarded as abnormal and foreign by the subject, confronting them with a healthy mind. The intelligence of the person is intact, and the obsessions are not caused by emotional or affective states. (p. 8)

Westphahl noted that individuals who experienced obsessions did suffer, secondarily, from anxiety.

Janet's (as cited in Nemiah, 1967) 1903 work described OCD as a pathological diminution of mental energy, creating a disruption of normal mental functioning; namely, will and attention. This results in an individual's being unable to control his or her thoughts and actions. Janet, who had a great interest in the disorder, appeared to be ahead of his time. He postulated that people could move from normal obsessive behaviour into obsessive compulsive personality and finally into obsessional neurosis. In his lifetime he collected over 300 cases of obsessive-compulsive neuroses (Kolada, Bland, & Newman, 1994).

Freud's psychoanalytic theories gave rise to renewed interest in obsessive thought and compulsive behaviour. His early formulation about obsessive neurosis gave rise to further exploration and to theoretical explanations. These explanations included describing the obsessive state as a manifestation of psychological defense mechanisms against repressed memories of previous sexual experience and guilt (Monte, 1995). Freud's (1973) famous case history of the "Rat Man" described in detail a case of obsessive neurosis.

Many literary sources have referred to obsessions and compulsions over the centuries. Stories date back to 1660, when Jeremy Taylor gave an account of William of Oseney, describing him as an overscrupulous man (Hunter & Macalpine, 1963). Boswell's 1791 biography of Samuel Johnson contains a telling description of obsessive compulsive behaviour:

> He said long after that he had been mad all his life, or at least not perfectly sane. His grimaces, his gestures, his mutterings, sometimes diverted and sometimes terrified people who did not know him. He would conceive an unintelligible aversion to a particular alley, and perform a great circuit rather than see that hateful place. He would set his heart on touching every post in the streets through which he walked. If by chance he missed a post he would go back a hundred yards and repair the omission. Under the influence of his disease, his senses became morbidly torpid, and his imagination morbidly active. At one time he would stand poring on the town clock without being able to tell the hour. A deep melancholy took possession of him, and gave a dark tinge to all his view of human nature and human destiny. Such wretchedness as he endured has driven many men to shoot themselves or drown themselves. But he was under no temptation to commit suicide. He was sick of life; but afraid of death; and

> he shuddered at every sight or sound which reminded him of the inevitable hour. (p. 109)

Boswell (1791/1979) commented to Johnson that the fear of death was natural to man. Johnson questioned this logic and wondered why he spent so much of his life performing rituals to keep away the thoughts of death. Indeed, Johnson worried and obsessed constantly about the awful hour of his impending dissolution, pondering how he should conduct himself upon his death (Boswell).

Presentation of Obsessive Compulsive Disorder

OCD can begin in childhood, early adolescence, or adulthood. The first stage of the disorder is often marked by microepisodes (Flament et al., 1988; King, Ollendick, & Montgomery, 1995), which are the abrupt presentation of obsessions and compulsions that last for a brief period of time and then disappear for a while (Warneke, 1993). Microepisodes may be a marker for the risk of development of the disorder (King et al.). For instance, Nicole, aged 12 years, suddenly develops a fear of germs on her toothbrush. This fear lasts for several weeks and then disappears. Weeks later she develops a need to turn the light switch on and off until it feels just right. Symptoms often become more bothersome and intense as time progresses.

Recent studies have shown that OCD is both common and geographically widespread (Hollander, Jenike, & Shahady, 1996; Jenike, 1989; Weissman et al., 1994) with amazing homogeneity of content and form across culture, time, and space. People in China, Africa, or Canada may all have a fear of hitting someone with their car; known in OCD language as the accident that never happened.

Contamination by germs is a fear experienced by individuals with OCD around the world. The similarities are amazing. Contamination fears involving disease have changed over the years. A fear of typhoid gave way to sexually transmitted diseases, and then to polio. The main fears of contamination now revolve around a fear of cancer and acquired immunodeficiency syndrome (AIDS). Interestingly, symptoms of OCD are almost identical in children and adults (Rettew, Swedo, Leonard, Lenane, & Rapoport, 1992).

Obsessions and compulsions are considered egodystonic (they originate from within). People with OCD report knowing that their symptoms are odd. They are fully aware that their thoughts and actions are strange and not rational, but have an uncontrollable need to carry out rituals to reduce the anxiety brought on by the obsession (Hollander et al., 1996). Characteristic secrecy and shame causes individuals to take great effort to hide rituals (Jenike, 1989; Rothenberg, 1998). Some individuals' fears are so intense that they will go to any extreme to avoid triggering their obsessions and consequent compulsions (Ladouceur, Freeston, & Gagnon, 1996). This leads to an avoidance of situations. Many people with OCD, because of the embarrassment of admitting to strange behaviour, try to treat themselves (D.S., personal communication, November 7, 1999).

Individuals with OCD take unreasonable responsibility for thoughts, events, and consequences beyond their control. Steketee, Frost, and Cohen (1998) found that subjects with OCD scored higher on six specific belief domains (responsibility, control, estimation of threat, tolerance of uncertainty, beliefs about

consequences of anxiety, and the capacity to cope) than do subjects with other anxiety disorders and control subjects, suggesting that cognitive domains appear to have more relevance to the OCD population. Bouchard, Rheaume, and Ladouceur's (1999) and Wilson and Chambless's (1999) studies lend support to the notion of OCD individuals having a heightened sense of responsibility.

People with OCD have problems inhibiting irrelevant information Karistianis (2003). Every thought that comes into their minds is considered to be important. Kozak and Foa (1994) have found through clinical observations that at times people with OCD do not always maintain insight into their symptoms. They may not regard their symptoms as unusual or excessive; they overvalue their ideas and believe them to be true. This overvalued belief makes OCD very difficult to treat with behavioural or cognitive therapies.

Common Obsessions and Compulsions

Specific obsessions and compulsions vary from person to person, but themes of a recurrent nature are found. Concerns with contamination are the most common obsessions, and cleaning and washing behaviours are the most common compulsions (Hanna 1995; Rapoport, Swedo, & Leonard, 1992; Sasson et al., 1997). Apter et al. (1996) found no significant differences in the obsessions and compulsions of boys compared to girls. This supports the findings of Zohar et al. (1992). Other common obsessive themes include sexual thoughts, aggressive urges, fear of losing something, symmetry, and somatic concerns. Other common compulsions include checking, repeating rituals, counting, and hoarding (King et al., 1995; Wright & Hewlett, 1994).

An obsession produces a great deal of anxiety. Completion of a compulsion provides a short-lived decrease in the anxiety (Rapoport, 1990). The ritualized compulsion is not necessarily realistically connected to the feared object or situation. In fact, the compulsion may be either unrelated to the outcome or clearly extreme (Rapoport). Often the dreaded outcome is unknown to the person with OCD (D.S., personal communication, November 7, 1999). Individuals with OCD are able to demonstrate some control over the compulsions; this partial voluntary control over compulsions makes OCD difficult to fathom (Rapoport).

Course of Obsessive Compulsive Disorder

The majority of individuals with OCD are very astute at hiding their symptoms of OCD; therefore, their disorder is often missed by physicians and nurses (Rapoport, 1990). Warneke (1993) found that clients with OCD were seldom hospitalized despite having a dysfunctional disorder. Physicians, thinking the disorder is rare, neglect to recognize the symptoms of OCD. People with OCD often hide symptoms of the disorder because of embarrassment, making diagnosis difficult (Sasson et al., 1997; Warneke).

Most people have OCD for about 7.5 years before diagnosis and treatment (Warneke, 1993). This number has been disputed by other authors; Hollander, Kwon, et al. (1996) found a 10-year gap, but when a comorbid condition such as depression or generalized anxiety disorder existed, there was a 17-year gap between onset of OCD and treatment. In another article Hollander,

Jenike, et al. (1996) noted a 17-year lag between appearance of symptoms and diagnosis.

Individuals may first seek help from dermatologists for sore, chapped hands, a dentist for bleeding gums, or an oncologist for fears of having cancer (McCormick, 1993). Fineberg, et al. (2003) screened 92 dermatological patients for OCD. Eighteen patients met the criteria for a diagnosis of OCD. Only one of these patients had previously been given the diagnosis. Dermatologists, dentists, and oncologists may find the following four screening questions helpful in recognizing and diagnosing OCD. Developed by Rasmussen and Eisen (1997), they have an 85% sensitivity rating for diagnosis:

> (1) Do you have to wash your hands over and over? (2) Do you have to check things repeatedly? (3) Do you have thoughts that come into your mind that cause distress and that you can't stop thinking about? (4) Do you need to complete actions over and over until they are just right or in a certain way before you can move on to the next thing? (p. 10)

If a client answers yes to one or more of the questions, then the Yale Brown Obsessive Compulsive Scale (YBOCS) symptom checklist and severity rating scale should be administered.

Sasson et al. (1997) suggested five similar questions that they felt should be a part of every mental status examination:

> (1) Do you wash or clean a lot? (2) Do you check things a lot? (3) Is there any thought that keeps bothering you that you would like to get rid of but can't? (4) Do your daily activities take a long time to finish? (5) Are you concerned about orderliness or symmetry? (p. 10)

No statistical sensitivity is given for this set of questions. Eddy and Walbroehl (1998) suggested similar questions. Periodic assessment, including use of the YBOCS, will assist in following the course of OCD.

Patterns of Remission and Relapse

Eisen et al. (1999) conducted a prospective study to examine the course of OCD in 66 individuals over a two-year period. Their findings support findings from earlier retrospective follow-up studies that showed OCD to be a chronic disorder (Goodwin, Guze, & Robins, 1969; Kringlen, 1965), but one that tends to wax and wane over time (Spitzer & Sigmund, 1997). Eisen et al. found that the probability of complete remission was 12% and of partial remission was 47%. The possibility of relapse was found to be 48%. They found no factors that could be used to predict partial or full remission of symptoms. Of the 66 individuals in the study, 51 received a selective serotonin reuptake inhibitor (SSRI) for at least 12 weeks. Only 12 individuals received behaviour therapy. The researchers concluded that full and lasting remission of OCD was low. They also suggested that therapists underutilize behaviour therapy.

Skoog and Skoog (1999) conducted a fascinating study. They studied 251 clients who were admitted to the Department of Psychiatry, Sahlgrenska University Hospital, Goteborg, Sweden, between 1947 and 1953 with a diagnosis of OCD. Using the same sample, although 75 were deceased and 32 were lost for other reasons, they conducted a follow-up study between 1989 and 1993. The same psychiatrist conducted the initial and second interviews. The second interview focused on the client's current state and on changes since the initial

interview. Clinical recovery was demonstrated in 48%, and only 20% showed complete recovery. "[Clinical] recovery was defined as absence of clinically relevant symptoms for the last 5 years or more. Complete recovery was defined as absence of both clinically relevant symptoms and subclinical symptoms for the last 5 years or more" (p. 123). Onset of OCD before the age of 20 was clearly related to a less hopeful outcome, especially in male participants. Price, Rasmussen, and Eisen (1999) stated that one of the areas lacking in the study of OCD is the natural history and course of the disorder.

Switching of Obsessions and Compulsions

There is little information available about the temporal characteristics and patterns of the typical course of OCD. Little is known about how and why the symptoms of OCD switch over time (Rasmussen & Eisen, 1998; Spitzer & Sigmund, 1997). One lady's symptoms changed from a fear of blushing to aggressive impulses to counting rituals to claustrophobia to a fear that others were slandering her. A male participant began with vague suspiciousness and changed to obsessive guilt and then checking behaviours with agoraphobia. One obsession and compulsion can abruptly stop and another replaces it. The individual with the disorder may not be immediately aware of the switch (D.S., personal communication, November 7, 1999).

Mataix-Cols, et al. (2002) tried to gain a deeper understanding of the switching of OCD symptoms. The research team followed a group of 117 OCD patients for 2 years. The YBOCS was administered 4 times during this period. Symptoms tended not to change, although some participants did report less

stability. Symptoms that did change mostly stayed within the same dimensions; therefore, a counter may have stopped counting their steps, but started counting how many times they chewed their food. Or washers may have stopped washing their hands after touching a gas can, but may have started washing their hands after reading each page of the newspaper. Mataix-Cols et al. found it rare that a checker would become a counter or that a counter would become a hoarder. The switching of obsessions and compulsions would be an interesting concept to research. Perhaps this is a topic I could address in future research.

Prevalence of Obsessive Compulsive Disorder

OCD was once considered to be a rare disorder and it was not until the 1980s that thorough epidemiological studies were conducted (Wright & Hewlett, 1994). OCD is now known to be a fairly common neuropsychiatric disorder (Hanna, 1995), ranking as the fourth most common psychiatric disorder in North America. Only substance abuse, phobias, and affective disorders are more common (Rasmussen & Eisen, 1992).

The now classic epidemiological study of OCD in adolescents by Flament et al. (1988) found an approximately equal number of females and males with the disorder. However, the male-female ratio is approximately 3:2 for children and adolescents, according to Hanna (1995). Rapoport, Leonard, Swedo, and Lenane (1993) supported this latter finding. Valleni-Basile et al. (1994) reported a 3% point prevalence rate in a community sample of adolescents. Apter et al. (1996) found a point prevalence rate of 3.6% in 16- to 17-year-old Israeli adolescents.

A 1998 study of 3,956 Edmonton residents revealed a 3.4% incidence rate for males and a 3.9% for females (Newman & Bland, 1998). Bebbington (1998) concluded that the prevalence rate of OCD is approximately 1%, making it twice as common as schizophrenia. Karno, Golding, Sorenson, and Burnom (1988) found a 3% lifetime prevalence rate in a study of five United States of America communities. The Cross National Collaborative Study examined the demographics and prevalence of OCD on four continents (Weissman et al., 1994). They found the age of onset of OCD, lifetime prevalence, and prevalence of OCD in males versus females consistent across continents. Age at onset was in the mid to late 20s. Lifetime prevalence was approximately 2% in the USA, Canada, Puerto Rico, Europe, and New Zealand. Women had a higher lifetime prevalence of OCD than men had, except in Germany. These figures led to the conclusion that more than 50 million people worldwide suffer with OCD. Over 600,000 Canadians are affected (Warneke, 1996). Pigott and Seay (1999) maintained that a true prevalence rate of OCD is still unknown.

Comorbidity with Obsessive Compulsive Disorder

There is a high comorbidity of OCD in adult and adolescent populations with major depression, other anxiety disorders, trichotillomania, and Tourette's syndrome (Hanna, 1995; Phillips, 2002; Rasmussen & Eisen, 1992; Toro, Cervera, Osejo, & Salamero, 1992). Antony, Downie, and Swinson (1998) found that 36% of OCD patients (n=87) attending a clinic in Toronto met the criteria for a diagnosis of OCD only. A further 28.7% met the criteria for one additional diagnosis, and 36.6% met the criteria for more than one additional diagnosis.

Yaryura-Tobias et al. (1996), with an n=391, found the most common comorbid diagnoses were major mood disorder (29.1%), specific phobia (27.9%), dependence on substances (14.5%), schizophrenia (11%), body dysmorphic disorder (9.7%), hypochondriasis (9.7%), Tourette's disorder (7.2%), anorexia nervosa (7.2%), social phobia (5.5%), impulse control disorder (5.5%), and agoraphobia (4.8%). Emerging literature is beginning to acknowledge a possible comorbidity of OCD and bipolar disorder (Perugi, et al., 2003).

Hollander, Jenike, et al. (1996) stated that up to two thirds of individuals with OCD experience at least one episode of major depression during their lifetime. Of OCD patients, 79% had clinical indications of depression. The depression began first in 36% of the patients, the OCD began first in 47% of the individuals, and OCD and depression occurred concurrently in 17% of the patients (Demal, Lenz, Mayrhofer, Zapotoczky, & Zitterl, 1993). Overbeek, Schruers, Vermetten, and Griez (2003) found comorbid OCD and depression affected treatment outcome negatively. It is evident that when OCD is associated with a comorbid condition, it is more challenging to treat.

(As an interesting note, Wright and Hewlett, 1994 made the claim that there are more people with OCD who are left handed. No other literature was found to support this claim.)

Theories of Causation and Treatment

Jenike (1998b) wrote that there are currently more than 20 varying ideas on what might be the etiology of OCD. The truth is that all that researchers can claim with any degree of certainty is that they do not know the cause of this

disorder. Many theories and models have been put forward for consideration. These include theories of injury, illness, or infection; biological models; cognitive models; behavioural models; and a combination of cognitive and behavioural models.

Injury, Illness, or Infection

Several reports of OCD associated with head trauma have been noted in the literature (Hillbom, 1960; Jenike & Brandon, 1988; Lishman, 1968). Jenike (1998b) presented a case of a young man who developed OCD following a motorbike accident. Symptoms developed immediately upon wakening from a month-long coma. Jenike suggested that this is an area that warrants further study.

OCD is more common in individuals who have had Sydenham's Chorea (Rapoport, 1989a; Rapoport et al. 1992). Sydenham's chorea affects the basal ganglia of the brain and is associated with rheumatic fever. According to Rapoport, approximately 20% of patients with rheumatic fever develop symptoms of Sydenham's chorea. She found significantly higher numbers of patients with obsessions among the group with Sydenham's chorea. No rheumatic fever patients without chorea developed symptoms of OCD.

A recent study by Alevizos, Lykouras, Zervas, and Christodoulou (2002) indicates the increased obsessions and rituals of schizophrenic patients treated with the antipsychotic medication risperidone. The severity of the OCD symptoms appears to be dose related and do lessen with reduction of the medication.

In the early part of the 20th century von Economo's encephalitis swept across North America in successive epidemics. Neurologic symptoms in survivors were common. These included Parkinsonism, oculogyric crises, movement disorders, and psychoses. After recovery from the encephalitis, numerous individuals developed OCD (Jenike, 1998b). This was the first reported link between a neurologic illness and OCD.

Biological Model

Evidence is growing to support the theory that OCD has a neurobiological basis (Delgado & Moreno, 1998; Flament & Bisserbe, 1997). Yaryura-Tobias and Bhagavan (1977) were the first to introduce the serotonin hypothesis of OCD. They found that persons with OCD had lower levels of the neurotransmitter serotonin in the brain synapses compared to persons without OCD. Numerous authors, including Flament and Bisserbe, Greist and Jefferson (1998), and Pigott (1996), have supported this finding. Delgado and Moreno (1998) however found that OCD may involve a dysfunction of the frontal cortex brain circuits and may not be a dysfunction of the serotonin system. Schwartz (1996, 1998) supported this finding.

Bergqvist, Bouchard, and Blier, upon completion of their 1999 study, concluded that among all of the antidepressant treatments available, only the SSRI medications have shown to be effective in treating OCD. Greist and Jefferson (1998) also concluded that the SSRIs are the drugs of choice. Six antidepressants are currently approved for treatment of OCD: (a) clomipramine (a tricyclic) and four SSRIs, (b) fluvoxamine, (c) fluoxetine, (d) sertraline,

(e) paroxetine, and (f) citalopram. Pigott and Seay (1999) conducted a meta analysis of the drugs used to treat OCD. The analysis indicated that clomipramine has superior efficacy to the newer SSRI medications in the treatment of OCD, but more recent controlled clinical trials have suggested that SSRIs have equivalent efficacy and notably fewer anticholinergic side effects.

Pigott (1996) stated that although serotonin dysregulation has been implicated in OCD, the specific pathophysiologic mechanisms of OCD have not been identified to date. This suggests that our understanding of OCD is elementary. The various antidepressants reduce symptoms by only 30% to 42%; hence, even the most successfully treated individuals are left with some fairly significant symptoms (Ladouceur et al., 1996). It is interesting to note that drug doses to treat OCD are generally higher than those to treat depression (Eddy & Walbroehl, 1998). No further information was offered to explain this finding.

Jenike (1998a) reviewed the literature on psychosurgery procedures for treatment of OCD, including cingulotomy, capsulotomy, limbic leucotomy, and subcaudate tractotomy. It is the intervention of last resort, but it is indicated for use in treating individuals who do not respond to other available treatments. Jenike concluded that some individuals could experience only partial relief of OCD symptoms. At the present time it is impossible to judge which surgical procedure is the best for a particular individual. To date no reports of negative consequences of psychosurgery have been reported in the literature (Jenike), although Jenike noted that in a small percentage of cases OCD symptoms were worsened. Dougherty, et al. (2002) prospectively assessed long term outcome of

OCD patients undergoing cingulotomy. They concluded that 32% to 45% of patients previously nonresponsive to medication and cognitive behavioural therapy (CBT) were partly improved after undergoing cingulotomy. Psychosurgery is still considered a viable option for patients with treatment resistant OCD.

Researchers from Belgium (Gabriels, Cosyns, Nuttin, Demeulemeester, & Gybels, 2003) have been examining the use of deep brain stimulation (DBS) as an alternative treatment to capsulotomy. The 2 patients receiving DBS showed continued improvement in OCD symptoms as measured by the YBOCS. Neither reported any harmful side effects on follow up.

Cognitive Model

Cognitive models have been used in an attempt to explain OCD and anxiety disorders in general. Cognitive therapy is based on the work of Aaron Beck (1976); Beck, Emery, and Greenberg (1985); and, more recently, Judith Beck (1995). Five strategies are utilized in carrying out cognitive therapy: (a) to consider intrusions as stimuli, (b) to identify negative automatic thoughts, (c) to challenge the reality of these thoughts, (d) to change the negative thoughts to nondistressing thoughts, and (e) to identify underlying dysfunctional assumptions (Greist, 1996; van Oppen, et al., 1995). The main theme within this model is that it is not the event, but rather the individual's interpretation of the event that results in a specific emotional response (Beck, 1976; Salkovskis, 1985; van Oppen & Arntz, 1994). Cognitive therapists assist individuals with OCD to identify their faulty beliefs and assumptions. These beliefs and assumptions are

examined and challenged utilizing a variety of techniques. These include Socratic questioning, determination of dysfunctional thinking, construction of alternative thoughts, and testing these thoughts through behavioural experiments (Salkovskis, Forrester, & Richards, 1998; Steketee, Frost, Rheaume, & Wilhelm, 1998). Salkovskis (1985) stressed that negative automatic thoughts are experienced as reasonable and ego syntonic, but obsessions are intrusive thoughts that evoke negative automatic thoughts, resulting in a need to ritualize.

Rachman (as cited in Clark & Purdon, 1995) in a 1981 article defined *unwanted intrusive thoughts* as repetitive, unwanted thoughts, images, or impulses that interfere with normal activity, are of internal derivation, and are hard to control. Muris, Merckelbach, and Clavan (1997) found that 54.7% of a "normal" sample of volunteers experienced the performance of rituals indicating that rituals are a common experience among a healthy "normal" population. According to Salkovskis and Campbell (1994), 80% of the "normal" population experience intrusive thoughts. Research conducted by Ladouceur et al. (1996) showed that 95% of normal individuals at times experience intrusive thoughts that cause anxiety. It is not understood why some individuals do not experience these intrusions. The content of the thoughts, images, or impulses in normals is similar to those experienced by individuals with OCD; however, OCD obsessions tend to be more frequent, are of longer duration, and cause more distress (Rachman & De Silva, 1978).

Salkovskis and Campbell (1994) tested the hypothesis that "personally relevant negative intrusive thoughts may be the direct precursors of obsessional

thinking" (p. 1). They further wondered whether intentional attempts to suppress a thought result in paradoxical enhancement of the thought. The researchers concluded that conscious suppression of thoughts could result in increased intrusion. They also found that distraction from the intrusive thoughts could play an important moderating role. Salkovskis, Westbrook, Davis, Jeavons, and Gledhill (1997) offered support for this finding.

As previously noted, several cognitive therapists maintained that perception of control plays a key role in the development and maintenance of OCD behaviours (Beck et al. 1985; Creamer, 1987; Lazarus, 1982, 1991, 1995; Salkovskis, 1985; Salkovskis et al., 1998). Purdon and Clark (1994) concluded that the degree to which individuals believed an intrusive thought might really happen was a significant predictor of the frequency and perceived uncontrollability of the intrusion. If a thought is appraised by the individual as having no negative consequences, no further processing is required; but if the thought is appraised as having a negative consequence, then further thought processing occurs, leading to a perception of threat, anxiety, and feelings of increased personal responsibility. This perception of threat and feelings of anxiety lead to the performance of rituals (Ladouceur et al., 1996; Lazarus, 1982; Rheaume, Ladouceur, Freeston, & Letarte, 1995).

Performance of the rituals not only decreases feelings of anxiety, fear, and discomfort, but also increases feelings of control and security (Franzblau, 1997). This leads to repetition of the ritualistic actions that increase the feelings of control and security. In an empirical study Franzblau found that individuals who

have ritualized behaviours tend to have greater feelings of anxiety and uncertainty, resulting in less confidence. This supports the notion that ritualized behaviours may be an attempt to regain feelings of control.

van Oppen and Arntz (1994) identified several shortcomings of conducting cognitive therapy with individuals with OCD: (a) some individuals reported not having negative thoughts; (b) some therapists mistakenly challenged the intrusion instead of the negative thoughts; (c) cognitive therapy may be effective only with obsessions; and (d) a therapist can easily be put into the role of constantly offering the individual reassurance that no harm will come to him or her or others. Despite these possible shortcomings, cognitive therapy has been shown to be effective in the treatment of OCD.

Behavioural Model

The behavioural approach to treat obsessions and compulsions dates back to 1903, the time of Pierre Janet (as cited in Baer & Minichiello, 1998), a French neurologist. In fact, Janet provided a description of what is now known as exposure therapy:

> The guide, the therapist, will specify to the patient the action as precisely as possible. He will analyze it into its elements if it should be necessary to give the patient's mind an immediate and proximate aim. By continually repeating the order to perform the action, that is, exposure, he will help the patient greatly by words of encouragement at every sign of success, however insignificant, for encouragement will make the patient realize these little successes and will stimulate him with the hopes aroused by glimpses of greater successes in the future. (p. 338)

Baer and Minichiello noted that Janet's description of exposure therapy continues to be accurate almost 100 years later. Physicians lost interest in Janet's work when Freud's (1909/1973) famous case of the "Rat Man" was published. Interest was aroused again by Meyer in the 1960s when he developed a method of completely preventing individuals with OCD from performing rituals (Baer & Minichiello; Meyer, 1966). Meyer called his method of treatment *apotrepic therapy*. It was made up of two elements: (a) putting an individual with OCD in real-life situations that resulted in increased anxiety and triggered compulsive actions, (b) preventing the person from carrying out the compulsive urges (De Silva & Rachman, 1998). This method became known as exposure and ritual/response prevention (ERP).

Behavioural therapists aim to reduce upsetting thoughts and feelings by changing behaviours of the individual (Greist, 1996). Researchers have found behaviour therapy to be more effective when the person with OCD perceives family members as being supportive of the therapy (Renshaw, Chambless, & Steketee, 2003). The behaviour therapy that is most effective for the treatment of OCD is ERP (Abramowitz, Foa, & Franklin, 2003). Cognitive therapy is most effective in dealing with obsessions, whereas ERP is most effective in dealing with compulsions.

ERP, as discussed above, is a fairly basic concept. It was developed from the basic principles of learning theory. Exposure involves gradually and repeatedly placing the individual with OCD in situations that provoke discomfort and fear (Baer, 1996; Dar & Greist, 1992). Once the individual is exposed to the

feared object or situation, response prevention is implemented. The individual is encouraged to refrain from performing the usual ritual (Dar & Greist). Initially, anxiety is heightened but slowly decreases when the performance of the ritual is prevented. Eventually, anxiety reduction no longer depends on the performance of a ritual, and the ritual is eliminated (Ladouceur et al. 1996; Thomsen, 1996; Warnock & Kestenbaum, 1996). For instance, John, who suffers from OCD, has an intense fear of germs. He is afraid of contracting AIDS from a chair in the medical office. He fears that he might then spread AIDS to his family and coworkers. Every time John sits in a chair he must wash his hands and forearms in a ritualistic fashion for approximately 30 minutes. Currently, John is avoiding all chairs unless he is 100% certain that they are clean. His ERP begins with an assessment of his fear. How strongly does he believe that sitting in a chair will give him AIDS? John realizes that the chance is actually minimal, but still he has lingering feelings of doubt. What if? What if there is a chance he could get AIDS? What if he did infect his family and coworkers? Next the therapist evaluates John's willingness to participate in the therapy. John must be willing to take the risk of contamination for the ERP to be effective.

First the therapist may model the exposure to the feared chair, and then John is encouraged by the therapist to sit in a chair, to touch the arms of the chair, to rub his hands over the seat, to rub his contaminated hands on his clothing. Once John is thoroughly contaminated, the response prevention is commenced. John is prevented from washing his hands for up to two hours. Initially, his anxiety will be very high, but gradually it will reduce. Eventually, John

will be able to totally stop the compulsive washing. If by chance during the time period of response prevention John does have to wash his hands, for example, after using the toilet, he would be reexposed to the feared chair.

Lindsay, Crino, and Andrews (1997) conducted a very interesting study to demonstrate the efficacy of ERP. Eighteen clients meeting the diagnostic criteria for OCD were randomly assigned to one of two groups: the ERP group or the anxiety management group (control). Members of each group received about 15 hours of therapy over a three-week period and were assigned homework after each session. The members of the anxiety management group did not show any significant change in OCD symptoms, but members of the ERP group demonstrated a dramatic decrease in symptoms. Using the YBOCS to measure symptoms, the anxiety group pretreatment score was 24.44 and the post score was 25.89; however, the ERP's pre score was 28.7 and post score was 11.0. This dramatic drop in YBOCS score indicated support for behavioural therapy.

ERP has some very positive benefits for the individual with OCD. ERP has long-lasting results; Marks (1997) discussed a case in which the individual remained almost cured of his OCD six years after treatment. He found that, in general, improvements persist throughout the years following treatment. ERP can be conducted in vivo, or it can be an imaginary experience (De Silva & Rachman, 1998). Family members can be taught how to be support people in assisting with ERP (Dr. S. Mitchell, personal communication, October 17, 1999; Marks). ERP can be conducted very effectively on an individual or group basis (Enright, 1991; Fals-Stewart & Lucente, 1994; Fals-Stewart, Marks, & Schafer,

1993; Marks). There is a move toward self-administered ERP with the assistance of manuals or computer programs (Baer & Greist, 1997; Schwartz, 1996; Griest, et al., 2002). ERP can safely be used in conjunction with medications. Schwartz (1996, 1998) showed evidence of CBT actually having a positive effect on brain function.

The drawbacks to ERP are few. Greist (1990) found that approximately 25% of OCD clients refused to participate in behavioural therapy. This lack of participation is due to an inability to manage the anxiety brought on by exposure to feared objects or circumstances. The need to refrain from performing a ritual may also be too difficult to manage. The lack of therapists trained to conduct ERP is a great problem. It is very difficult for people with OCD to find appropriate help for their disorder because of limited access to mental health personnel (Goodwin, Loenen, Hellman, Guardino, & Struening, (2002). Marks (1997) found that relapse prevention in the way of booster groups was often necessary to maintain improvements.

Combining Biological, Cognitive, and Behavioural Therapies

The concepts of cognitive theory and behavioural therapy evolved separately. A strictly behavioural approach was challenged by the cognitivists, and the result has been a combination of behavioural and cognitive approaches to OCD (Hand, 1998). Gradually, they are being integrated, and therapists are conducting CBT. McKay (1997) completed a two-year follow-up for clients who had completed ERP and cognitive therapy and were then participants in a

maintenance program; all six of the participants maintained improvement at the 24-month mark.

It is commonly thought that CBT combined with medication is more effective than either approach on its own (Hand, 1998), but this has not been shown in any controlled trials (Liebowitz, 1998). van Balkom et al. (1994) completed a meta-analysis on the treatments available for OCD. They compared antidepressants, behaviour therapy, cognitive therapy, and a combination of these methods. The serotonergic antidepressants and behaviour therapy (separate and in combination) were found to be significantly more effective than a placebo. Behaviour therapy was more effective than treatment by antidepressants when rated by the people with OCD. Overall, participants rated combination treatments as more effective than antidepressants alone; however, assessors found no differences among the three therapies. Support of the concept of combining CBT and SSRIs is offered by several researchers (Franklin, et al. 2002; Kampman, Keijsers, Hoogduin, & Verbraak, 2002). Another study found CBT or strictly medication to be more effective than no treatment (O'Connor, Todorov, Robillard, Borgeat, & Brault, 1999). The researchers also concluded that the combination of CBT and SSRI medications resulted in greater efficacy. They found introducing CBT after commencement of SSRIs to be more beneficial to the individual with OCD. More recent literature (Denys, van Megen, & Westenberg, 2002; Francobandiera, 2002; Hollander, et al., 2002) suggests the addition of one of the atypical antipsychotic medications be added to the combination of CBT and SSRIs. This combination of treatments is especially

effective in treatment resistant OCD. Biological, cognitive, and behavioural approaches can work in conjunction with each other.

In 2003, Kirkby conducted an extensive review of the OCD literature. He concluded OCD is a complicated disorder and that many treatments have been tried over the years. Some have had a good success while others proved to hold no promise in reducing obsessions and compulsions. Kirkby offers hope to people with OCD by concluding that research is converging on a basic understanding of the disorder and the effective treatments.

Experience of Obsessive Compulsive Disorder

Several authors have written about their experience of living with OCD. Califano (1996) discussed her need for perfectionism. Case (1995) also wrote about her perfectionism, but added thoughts about how her spirituality helped her cope with OCD. Callner (1995) shared with the reader some of the solutions that helped him deal with his OCD. Hull (1995) wrote about how she learned to live with OCD. Jon Grayson (Grayson & Frankel, 1995), an OCD therapist, took a group of people with OCD on a camping trip. In the article the many challenges experienced by the campers were discussed. Imagine someone with a fear of contamination touching a gas can, tromping through a swamp, or eating food prepared by someone who has not washed his or her hands. Grimm (1995), Haase (1998), and Susin (1997) addressed the experience of being the parent of a child with OCD. Several authors presented portions of case studies (Dumont, 1997; Mnuchin & Hollander, 1995; Rapoport, 1989b). These case studies provided a picture of OCD but did not give a deep understanding of the disorder.

Although many researchers have provided descriptive accounts of OCD clients' experiences, most of these experiences have been interpreted and given meaning by the researcher; for example, Judith Rapoport's (1989b) book *The Boy Who Couldn't Stop Washing* or Raeann Dumont's (1997) book *The Sky is Falling.* O'Neill (1999) interviewed a client with OCD and then interpreted the interviews. It seems to me that she tried to make logical sense of the OCD when in reality OCD does not make sense. It is this oddness that makes OCD so interesting.

Conclusion of the Review of the Literature

In this review of the literature I have offered the reader a general description of OCD and defined obsessions and compulsions. A brief history of OCD demonstrates how the beliefs and treatments have moved from thoughts of demons and exorcism to biological, cognitive, and behavioural etiologies and cognitive-behavioural therapies in conjunction with medications. I have given descriptions of common obsessions and compulsions and the course of OCD and reviewed the interesting notion of switching obsessions and compulsions. I have noted that the area of switching obsessions and compulsions warrants my further investigation. The review of the literature also highlighted other disorders that may present with OCD. It is now known that OCD is more common than originally thought, affecting approximately 600,000 Canadians. Theories of causation were discussed, and it was noted that the cause of OCD is still not clearly understood. Therapists now recognize that a combination of biological, cognitive, and behavioural treatments may be the most beneficial in the

treatment of OCD. In discussing the experience of OCD, I identified a gap in the literature. Although there is abundant literature about the epidemiology, prevalence, assessment, and treatment of obsessive compulsive disorder, no articles have addressed the lived experience. This gap in the literature led me to the research question, "What is the lived experience of obsessive compulsive disorder?"

The Research Question

As the question came clear to me I began my search for understanding. The purpose of my research is to enrich my own and the reader's understanding of the lived experience of OCD. How can I know that my research question "What is the lived experience of obsessive compulsive disorder?" fill the gap that was identified in the review of the literature? Articles/books written by, for example, Rapoport et al. (1992), Schwartz (1996, 1998) or Warneke (1993, 1996) demonstrated the essential contributions that have been added to our knowledge of clinical assessment and treatment of OCD. However, no articles have addressed the everyday experience of OCD. Many clinicians have provided descriptive and compelling accounts of individual experiences with OCD, but these experiences have been interpreted and given meaning by only the clinician (O'Neill, 1999). How would the experiences of OCD look if the individual with OCD were called to reflect on the interpretation and meaning of the experience? What is the difference between the descriptions offered in the literature and a phenomenological description? Description offers us a picture of an experience, but van Manen (1997) stated that the phenomenological description aims to shed

light on lived experience. Good phenomenologic description illuminates some aspect of the lifeworld; "it resonates with our sense of lived life" (p. 27). To get in touch with my participants' lifeworld, I planned to utilize hermeneutic phenomenologic inquiry.

Being able to take the words of an individual with OCD, interpret them, and provide a rich text that illuminates their lived experience made me confident that my research question is correct. It also confirms for me that hermeneutic phenomenology is the best research method for this inquiry.

CHAPTER III

THE METHOD: HERMENEUTIC PHENOMENOLOGY

Phenomenology is a human science, and when researchers utilize a phenomenological method, they begin with life situations rather than empirical data as one would in a natural science. The research question does not deal with quantitative matters but asks, "What is this person's experience in his or her lived world?" Therefore, my research question, "What is the lived experience of obsessive compulsive disorder?" fits very well with this method of research.

Some researchers define *phenomenology* as a description of lived experience and hermeneutics as an interpretation of experience. van Manen (1997) states that all description is ultimately an interpretation of that which has been described. In this interpretive inquiry the term phenomenology will refer to both descriptive and interpretive components.

Phenomenology is the systematic attempt to uncover, understand, and illuminate the structures of the world of everyday life (Anderson, 1989; Swanson-Kauffman & Schonwald, 1988). It is the inquiry of lived experience (van Manen, 1997). It gives us a form of knowing through experience and language. The goal of phenomenology is not to generate theories or models, but to describe the phenomenon under study (Bailey, 1997; Morse & Field, 1995). It is to "transform lived experience into a textual expression of its essence" (van Manen, 1997, p. 36). I agree with van Manen that phenomenology begins and ends in the lived

world of everyday experience and leads to practical knowledge of thoughtful action.

In researching OCD I did not want to accept or reject particular hypotheses, I did not want to develop tools or scales for measuring severity of the disorder, and I did not want to examine etiology. I wanted to get closer to and uncover the essence of what it is like to live with OCD. I wanted to gain a deep description and understanding of the lived experience of OCD. To succeed in doing this, I followed the phenomenologic approach suggested by van Manen (1997) that demonstrates the dynamic interplay among six research activities:

> (1) turning to a phenomenon which seriously interests us and commits us to the world, (2) investigating experience as we live it rather than as we conceptualize it, (3) reflecting on the essential themes which characterize the phenomenon, (4) describing the phenomenon through the art of writing and rewriting, (5) maintaining a strong and oriented pedagogical relation to the phenomenon, and (6) balancing the research context by considering parts and whole. (pp. 30-31)

Turning with Commitment

My own interest in the experience of OCD grew out of an experience I had as a young child. My neighbour had a fear of germs and performed many elaborate rituals to keep her family safe. I became a part of those rituals when I visited their house. My interest grew when I began working as a nurse on a psychiatric unit that occasionally admitted OCD patients. The opportunity to work with a physician who specialized in treating individuals with OCD made me begin to ask questions about the disorder. My commitment to this question has been

unwavering for many years. To conduct this phenomenologic research is a personal undertaking; it has become a part of me.

Many philosophers and researchers suggest that to conduct a phenomenologic study the researcher must bracket, or set aside, his or her beliefs about a topic. This is to prevent one's own beliefs from influencing the data. In keeping with the thoughts of van Manen as a researcher, I brought my beliefs, assumptions, and presuppositions forward; acknowledged them; and was aware of them as I conducted the inquiry (M. van Manen, personal communication, September 14, 1998). To identify my own beliefs I started a personal journal. Reflecting on the review of the literature gave me a strong starting point to become aware of my thoughts, ideas, and beliefs about OCD.

van Manen (1997) reminded me that the insights and descriptions gained from a piece of phenomenological work are only one interpretation of a description. Another researcher could take my descriptions and write a completely different piece of work. My description of the lived experience of OCD did not mean that another complementary or even richer and deeper description would not be written.

Experience as Lived

As a phenomenologist, my aim was to establish a renewed contact with the original experience of my participants (van Manen, 1997). I started this process of data collection by asking my participants, who have had the experience of OCD, to write anecdotes. I followed the suggestion of van Manen when I asked them to describe their experience as lived. I wanted them to avoid

causal explanations, generalizations, and interpretation. Initially I asked participants to use the four existentials of spatiality, corporeality, temporality, and relationality as a guide for reflection (van Manen). I quickly discovered that I did not need to explain the existentials because they are a part of our daily lives, a part of our being in the world. In the writing I encouraged them to focus on one particular event and asked them not to beautify the event with flowery language. The following is an example of an anecdote about living with OCD written by Leah:

> It was my husband's birthday on Tuesday, and I wanted to buy him a cake. I thought about it all day on Monday. I planned every step I would have to take to get in and out of the store. Monday morning I woke up, and I knew right away that it was going to be a bad OCD day. It took me twenty minutes to get my underwear on **just right**. My anxiety and frustration was mounting. I hopped, skipped, and jumped my way down the hall to the kitchen. I couldn't get the feelings of doubt to leave my mind. I knew that if I didn't get out of the house **just right**, something horrific would happen. It took me four hours to get to the store. I walked through the IGA, counting my steps: one, two, three. One, two, three. No, I did that wrong. Back to the door to start over, only this time I have to do it all three more times. I am certain people are watching me. Finally, I get the cake. As I leave the store and start to walk between the two sets of doors, I notice a piece of paper on the floor. I feel compelled to pick it up. The next thing I know I am down on my hands and knees picking up all of the pieces of paper, bits of lettuce, twist ties, and garbage between the doors. I truly believe that if I do not pick up every piece of garbage, something will happen to my husband. Despite the humiliation of crawling around on my hands and knees and stuffing garbage into my pockets, I can 't stop. The fear and doubt are too great. (Haase, 2002, p. 75)

Leah's anecdote is very powerful. It evoked feelings in me. I could only wonder what feelings were evoked for her as she shared this story with me.

Research anecdotes were not my only route to gather data for my inquiry. Conversations were used as a means for exploring and gathering experiential narrative material and for developing a conversational relation with a person in order to discuss his or her experience of OCD (van Manen, 1997). I began the conversations with a statement such as, "Tell me about your experience with OCD." Conversations provide rich data for the inquiry.

In my research for this inquiry I also used literature that described obsessions and compulsions. Who can forget Lady MacBeth as she tried to rid the blood of Duncan, King of Scotland, from her hands? "Out, damned spot! out, I say!" (Shakespeare; as cited in Inglis, Stauffer, & Larsen, 1952, p. 184). Well-written literature gives us the opportunity to experience events and emotions. Even fairy tales can be used as material to reflect on. I remember the obsessive fear of Henny Penny, who believed that the sky was falling. Literature about OCD stimulated reflection for my participants and me.

Poetry or works of literature were used to capture the essence of OCD. Tracing etymological origins of words put me in touch with an original form of the word and shed light on a deeper meaning (van Manen, 1997). I explored idiomatic phrases that make sense only to individuals with OCD, for instance, the phrase "just right." There were many ways that I was able to collect data to establish renewed contact with the original experience of OCD.

Reflecting on Essential Themes

My purpose in engaging in phenomenologic reflection was to try to determine and explicate the meaning of OCD. During the analysis phase, which coincides with data collection, I examined all texts that I had collected and elicited themes. "Theme is the experience of focus, of meaning, of point. Theme is the needfulness or desire to make sense. Theme is the process of insightful invention, discovery, disclosure" (van Manen, 1997, pp. 87-88). As I read over the data I asked myself, "What is the meaning here? What is the point that is being made?" I anticipated I would be reflecting on themes such as: (a) Do obsessions come from inside or outside the body? (b) What is the meaning of "just right"? (c) What is the experience of counting every step? (d) What causes obsessions and compulsions to suddenly disappear and new ones to begin? I was surprised when the emerging themes differed from what I had anticipated. Identifying and exploring themes allowed me to get closer to the truth of OCD.

van Manen (1997) suggested three approaches to the analysis of data to uncover or isolate themes: (a) the wholistic or sententious approach, in which we attend to the text as a whole; (b) the selective or highlighting approach, in which the researcher reads a text several times to determine what statement(s) or phrase(s) appear to be essential to the description of the phenomenon or experience being described; and (c) the detailed or line-by-line approach, in which the researcher looks at individual sentences and identifies what the sentence reveals about the phenomenon or experience being described. Finally, the researcher writes the thematic statements into phenomenologically sensitive

paragraphs (van Manen). I anticipated that I would use each of the approaches as I reflected on essential themes in my analysis of the data.

van Manen (1997) suggests alternative ways of structuring a study including (a) thematically, (b) analytically, (c) exemplificatively, (d) exegtically, (e) existentially, or (f) you may invent an approach. I decided to use the existential approach. My anecdotes have been divided among the existentials of temporality, spatiality, corporeality, and relationality. These existentials are common to all human beings in our everyday situations and relations. The four existentials guided my questioning, reflecting, and writing.

Act of Writing and Rewriting

Phenomenology is mainly a writing activity. The object of phenomenology is to create a phenomenological text (van Manen, 1997). The writing invited further reflection as I reflected on meaning and searched for the right words to describe the experience of OCD.

The question of reliability and validity enters the picture of any research activity, but these terms cannot simply be applied to studies using a phenomenologic method (Yonge & Stewin, 1988). Validity lies in the power of the text to elicit recognition of the experience. How did I check that my themes were correct? How did I ensure that I did not misrepresent the participants? I took my identified themes back to my participants. I asked my supervisors to read some of the texts that I created and to verify that I had identified essential themes, and I asked the participants to read and reflect on the themes that I identified to see whether they rang true for them. With the participants I constructed the story of

OCD. Our shared perception of the themes helped us make explicit the structure of the meaning of the lived experience of OCD (van Manen, 1997). I knew that my text was valid when the description of the phenomenon that emerged spoke to the participants and readers, when they gave the text the "phenomenologic nod" of acceptance.

I combined portions of anecdotes or conversations to elicit a thick description of OCD. Because I do not have OCD myself, I once again had to seek the experience of my participants and ask them to review my writing. I asked them to confirm that I had captured the essence of lived experience of OCD, and we constructed the story together. I did not simply assume that my interpretation was correct. My writing reflected the true experience of living with OCD.

Continuous and Strong Orientation

I acknowledge that I might have had times when my strong orientation to OCD waned, but I had to ensure that this did not happen. If it did, I would spend valuable time getting side tracked and wandering aimlessly. Having entered into an ongoing relationship with my participants allowed frequent contact with people who have OCD; they are the people who kept my interest alive. I wanted to know and understand lived experience of OCD. I might have made a difference in their lives. Bergum (1998) felt that both the heart and the mind must be stimulated, because neither mind nor emotion alone is adequate. When my heart and mind were stimulated, my interest would not falter.

I kept a personal journal that included reflections on my feelings that were aroused. In this journal I included an audit trail to allow my supervisors to know where I had gone and where I planned to go with my research. Presenting an audit trail was not meant to provide a means to allow reproduction of the inquiry; the quality of the inquiry was not based on its reproducibility (Stake, 1995). Rather, it provided a means for purposeful reflection. Reflection on the writings in the personal journal helped to keep me orientated to the lived experience of OCD.

Considering Parts and Whole

Considering the parts and the whole means that I continually needed to be cognizant of the overall design of my inquiry/text and constantly aware of the interplay between the parts and the total textual structure (van Manen, 1997). I had to be cautious of not getting so involved in the "What is this OCD?" that I failed to unveil the text. I occasionally stepped back and looked at the whole to ensure that I had not missed any of the parts.

Phenomenology calls for an openness that allows for changing directions and exploring techniques, procedures, and sources of data that are not always obvious at the onset of the research (van Manen, 1997). van Manen suggested two questions to help keep the inquiry focussed. I kept these questions in mind as I conducted my inquiry: (a) "What is the lived experience of OCD like?" (b) "What is the meaning and significance of the experience of OCD?"

Because phenomenology calls for an openness to explore, I did not set my research plan in stone. I was open to changing directions and exploring new

and different methods of data collection and analysis, and whatever exciting challenges and opportunities presented to me. I reflected on my personal journal for insight into possible directions to explore. I was continuously aware of the part and the whole.

Participants in the Inquiry

Participants of this inquiry were volunteers who have had the experience of OCD and were willing and able to reflect on their experiences. I contacted the College of Physicians and Surgeons for a listing of all psychiatrists working in a catchment area of a large Canadian city. A recruitment notice (Appendix B) was mailed to each psychiatrist's office. Interested participants contacted me via phone for further information and to set up a time for tape recorded conversations. They were made aware of probable time commitment, including (a) conversations, (b) discussion of emerging themes, and (c) final validation of the text. In all, approximately three hours were necessary. My participants were gathered in only two weeks. I turned away many people who expressed interest in participating.

As previously noted, my research plan was not set in stone. I was open to changing directions and exploring new and different methods of data collection and whatever exciting challenges and opportunities presented to me. I anticipated that I would need to have two or three conversations with no more than 20 participants to obtain rich data and to validate the text. In the end I had three conversations with 2 participants, two conversations with 1 participant, and one conversation with the remaining 11. After having the taped conversations

transcribed, I returned to the participants and asked them to read their transcript. Two participants asked me to leave parts of their conversation out of the final paper. All 14 provided me written ethical consent to use their interviews.

Conversations took place in a private location that was convenient to the participant and me. Time was spent gaining rapport and a sense of trust with the participants prior to asking them to describe their experiences with OCD. The participants were given an information letter, written at a Flesch-Kincaid grade level of 7.4 (Appendix C) and asked to sign the informed consent form (Appendix D) prior to commencing the conversations.

Ethical Considerations

Whenever a researcher chooses to study an individual with a mental disorder, the questions of vulnerability, power, and coercion must be addressed. The word *vulnerable* comes from the Latin *vulnerabilis,* meaning wounding or open to attack (Hoad, 1986). Are the mentally ill a vulnerable population? Are they open to attack by researchers conducting a phenomenological study?

Several authors referred to the mentally ill as having reduced autonomy, with decreased ability to give informed consent and question whether vulnerable persons should be asked to participate in research studies (Levine, 1986; Raudonis, 1992; Usher & Holmes, 1997; Watson, 1982). In the past the psychiatric population has been considered incapable of making decisions about their own lives. This view is changing, and health care workers now feel that psychiatric clients should be active collaborators with the right to decide for themselves (Olofsson, Gilje, Jacobsson, & Norberg, 1998). This sense of

increased autonomy makes them less likely to be the victim of coercion (Shils, 1972; as cited in Ramos, 1989).

If we do not enter the world of the vulnerable, how will we uncover what is needed to improve their lives? Frank (1995) observed that the seriously ill are wounded not only in body, but also in voice. Frank believed that these people need to become storytellers to recover the voice that their illness and its treatments have taken away. It is important that we, as researchers, obtain participants' perceptions and hear their stories to promote a strong relationship (Vellenga & Christenson, 1994). In my research I gave voice to the stories of my participants.

I was aware of the power difference that may exist between researcher and participant. A participant should never take part in an inquiry/study or share information merely to please the researcher (Holloway & Wheeler, 1995). The researcher must understand the feelings of obligation that a participant may experience. Often they feel powerless to deny the researcher access to their lived experience (Holloway & Wheeler). Ramos (1989) explained that because the participant is on "home turf," he or she is often more knowledgeable than the researcher, resulting in a change of power (p. 59). This more balanced relationship is the key to meaningful information sharing:

> When the balance of power is shifted, participants are likely to tell "stories"; . . . interviewing practices that empower respondents also produce narrative accounts. . . . Through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own

> story, but to apply the understanding arrived at to action in accord with one's own interests. (Mishler, 1986, p. 119)

I discussed my role as researcher with my participants. My aim was to empower them, to give a voice to their stories.

A nurse conducting a phenomenological inquiry constitutes a fine balance between conducting the research and having a nurturing concern for the participants (Ramos, 1989). The relationship between the researcher and the participants is fundamental to the success of the inquiry. The nonnumeric nature of the data means the researcher must continually validate the text with the participants, resulting in a close interpersonal relationship (Leininger, 1985) that exerts a permanent effect upon both researcher and participants (Parker, 1984). The boundaries between the researcher and the participants can become blurred; therefore, roles must be consensually defined (Ramos).

In conducting a phenomenological inquiry I was aware of the possible effects that the research might have had on my participants, as suggested by van Manen (1997). On one hand, they might have felt a new sense of hope, increased insight into OCD, or a certain thoughtfulness; but on the other hand, they might have sensed a feeling of discomfort, anxiety, or self-doubt. Bergum (1991), in her study of women's transformation to motherhood, found that the fact that women spoke about their experiences made a difference in their lives: "It raised their own awareness of what they were going through and resulted in reflection that may not have occurred outside the research environment" (p. 67).

My ability to establish a sense of trust with my participants and to take a non judgmental stance was a key factor in eliciting deep, rich information

(Cowles, 1988). What would I have done if they had disclosed information that might have been too sensitive to record? Glazer (1980) noted that, on one hand, a participant has his or her own reasons for wanting to take part in a study, has signed consent, and is able to decide what information he or she will share. On the other hand, some participants may have difficulty setting boundaries on the subject matter they share. As the researcher, if I had believed that a participant was overdisclosing personal information, I would have addressed the issue at the time, ultimately allowing him or her to decide whether or not to include the information in the final text.

As noted earlier, individuals with OCD are often fearful about disclosing details of their disorder. I became attuned to participants and their possible discomfort in sharing uncomfortable aspects of their OCD. I was nonjudgmental and supportive. At times it was appropriate for me to share stories from other people with OCD to help normalize a participant's experience.

It was important as a researcher that I be aware of possible difficult situations that might have arisen. I had to have an action plan in place. What would I do if the participant became upset or wanted the tape recorder turned off? I explained, prior to commencing the conversation that he or she could indicate at any time if they wished to have the tape recorder turned off. I also explained that the participant always had the option of not having parts of the conversation transcribed. I still listened to them discuss their concerns, if they wished. My experience as a mental health nurse helped me deal with emotional upset. I encouraged participants to keep a personal diary for writing down their

thoughts and describing their feelings. None of the participants chose to keep a diary. I made participants aware that I was prepared to make a referral to another professional if indicated (Appendix E). I was also aware that if the participant was extremely emotionally distraught, he or she might have wished to withdraw from the research.

It is known that OCD can be very stressful on a marriage and family, perhaps even leading to an incident of abuse. The abuse may involve children in the family or adult members of the family. Participants were informed that in the event of a breech of a professional code of ethics and/or legislation, I would be required to report the incident.

Qualitative research can be very difficult emotionally for the researcher as well as for the participants. What would I do if I found myself in a position of emotional distress because of the findings of the research? I ensured that I had scheduled times to speak to my co-supervisors, Dr. Olive Yonge and Dr. Jeanette Boman, about any stressful concerns and feelings. I kept a personal journal to write about my thoughts and feelings. One of the most important things I did was to move back from the research and take a break: go for a walk, exercise at the gym, or read a novel. Morally, I might have been obligated to leave the inquiry (Fowler, 1988).

After spending time developing a strong relationship with my participants, I was faced with the fact that the inquiry was coming to an end. Holloway and Wheeler (1995) noted that the continuous, intimate nature of the researcher-participant relationship creates trust and friendship. How would I manage the

ending of the relationship? I began by setting boundaries on the length of the relationship, reminding participants that the inquiry would not proceed forever. Perhaps a ritual to celebrate the close of our time together would be appropriate.

Important issues that I had to address when obtaining consent to participate was the area of anonymity and confidentiality. It was necessary for small changes to be made to the text to ensure anonymity. Participants were assured that their identity would not be disclosed. A code number was assigned to each participant. Audiotapes, transcripts, and journals were secured in a locked cupboard. Tapes and so on will be destroyed after seven years unless ethical approval is sought for secondary analysis of the data.

Ethical clearance to conduct this study was sought from the Health Research Ethics Administration Board. Participants were given the personnel page (Appendix F) and information letter (Appendix C) and were asked to sign the informed consent form (Appendix D). They were free to withdraw consent at any time. If the participants did choose to share their stories, was it sufficient to have an informed consent signed at the beginning of the research project? I believed I would need to revisit the consent on several occasions. Munhall (1989) referred to this as *process consent*. When I entered into the phenomenological journey with my participants, there was no way to know where it might have led us. As we made turns and new discoveries, revisiting consent by reading and signing the consent form for a second time ensured that we were still working together to construct their story of the lived experience of OCD.

In the following eight chapters I do two things. First I show the nature or the appearance of OCD by comparing it with ordinary human experience. The examples of ordinary experience are generally my own, but on occasion I use the example of others. I begin with an anecdote of ordinary experience and immediately follow with an OCD anecdote. In placing these anecdotes side by side, the differences between ordinary experience and OCD experience are shown. I could have simply stopped writing at that point, but I did not want to leave the impression that OCD is just strange. Having seen the difference, in the following chapter I move beyond that and show the sameness of ordinary experience and OCD experience. I did not put OCD side by side with ordinary behaviour; rather, I put it side by side with behaviours that are sort of like OCD, but not OCD. In showing the sameness, OCD becomes more understandable. However, even in showing the sameness, a difference will be evident.

CHAPTER IV

HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF RELATIONALITY?

Lived relation or *relationality* is "the lived relation we maintain with others in the interpersonal space that we share with them" (van Manen, 1997, p. 104). It is through relationships with the other and with self that our own reality is confirmed. Relationality refers to the connections we make through social contacts with others (Hayne & Yonge, 1997). It is through relationships with others that our differences and commonalties are brought to light. When a disorder such as OCD is present, relationships can be greatly affected.

Wanting to, Not Wanting to, Having to

I recall being so excited and feeling very important when my parents went out to dinner one night and left me in charge of my little sister for the first time. I was about 12 years old, and Janet was 7 or 8. My excitement grew all day long as I anticipated being alone. When they finally left, I was full of importance and took their directions very seriously: "Do not let anyone into the house"; "If anyone phones, for us just take a message"; "You may have two cookies and a banana for a snack just before bed, and remember to brush your teeth." Janet and I had a great time. We played Beatles records and danced around the kitchen. We had fun pretending we were singing stars. Finally, it was time to have our snack and go off to bed. I slept on the bottom bunk and Janet on the top. I tried to stay awake until Janet was asleep and my parents came home. I heard the gentle

rhythmic breathing of my little sister, but I was fast asleep by the time my parents arrived home. The next morning we excitedly shared our story of dancing to the Beatles, eating our snack, and going to bed on time. My parents exchanged a funny smile.

Anne too, is left alone for the evening while her parents go out to a quiet dinner:

> On the front page of the newspaper it says that two people had been killed in their own home, just last night. My parents were out for dinner last night. What if they killed those two people? I have to prove their innocence. They left the house at 6 pm, but when did the murder happen? I phone the police to get some details. They don't give me much information. Do they know I know who murdered those people? I try to trace my parents' steps. Were they anywhere near the murder scene? I am panicking. I have to know. I call the police again for more information. They ask for my name and number, and I hesitantly give it to them. I phone my mother at work to confirm they had gone directly to the restaurant. Just to double check, I also call my father and ask him the same question. I turn on the radio, hoping to hear the news. Nothing. Now what do I do? Should I turn my parents in to the police? I have to find a way to prove they were at the restaurant for the entire evening. I phone my mother to see if they had gone to dinner with friends, although I know they went alone. I feel so scared. What will I do when my parents are in jail? Who will take care of me? I turn the noon news on the TV just in time to hear, "A suspected double murder last night has now been confirmed to be a murder suicide." I collapse in exhaustion. I question myself: "How could I have possibly thought that my parents would commit a murder?"

Anne's experience of being left alone is quite different from my experience. Her night results in a day full of terror, whereas I spent the following day full of pride and excitement.

In this story Anne, as a teenager, struggled to maintain a relation with her parents. Many teenagers will tell you about the struggles they have in forming a relationship with their parents. There are issues of wanting and needing independence while at the same time not wanting it, and wanting and needing parental guidance but not wanting it. When Anne was a teenager, on top of the usual challenges, she had obsessions and compulsions that interfered with the relationship she had with her parents. Compulsions are also about wanting, needing, and not wanting. She wants to prove the innocence of her parents, she is actually driven to do this, and yet, at the same time she recognizes her actions and worries as nonsense. She wonders how she could possibly think of her parents as murderers. How did the obsessive fear of her parents being murderers even come to be?

As a parent it is easy for me to imagine a quiet evening, away from the children, with just my spouse. It is true that our conversations may touch on what our children have been doing with their lives; we may even express some frustration with choices they are making. As we chat we enjoy the growing separation from our teenaged children and begin to glimpse a life that does not revolve around them. But what happens to Anne's parents when Anne does not allow them to move on in their lives? Her obsessions and compulsions constantly draw them into her life, into a relationship they do not want. Anne is a nuisance in

their lives. She is continuously having bizarre ideas and thoughts about them, and she is constantly checking up on their whereabouts. She phones them at work, several times a day, with different fears and worries. Most teenagers do not want their parents involved in their lives, yet Anne keeps bringing them into her life. It is not that she really wants them to be a part of her life; it is that she has to have them as a part of her life. Why does she have to?

Anne is a worry for the parents. They question how she will be able to live on her own, how she will finish school and university, and how she will ever find a job. When parents worry for a child, they tend to fret and fuss, often making a nuisance of themselves to the child (van Manen, 2002). In this relationship each is a nuisance in the other's life. The parents, most likely, would like to see Anne get on with her life. They would like to see her having fun with friends, perhaps dating, and enjoying school activities. But Anne is caught in obsessions and compulsions. She is caught in wanting to, not wanting to, and having to.

In the Grocery Lineup

To have a relation means to carry back to (M. van Manen, personal communication, November 2, 2002). It means that I will see you again and you will see me again. When I am in the grocery lineup, I am always behind or ahead of someone different. Some shopping days I will greet the stranger in front of me, but most often I stand quietly. I never feel that I have to talk to the person. Occasionally, if the person makes eye contact, I may engage in a brief, superficial conversation. I may ask if they have plans for the weekend. I do not really listen to their answer with great interest; I could care less whether they are

going to the lake or flying to Europe. Once I am through the lineup, I have no desire to search that person out again. His or her image quickly fades from my thoughts, and nothing calls me back.

In the following anecdote you will see that a similar experience is different for Leah. Something calls her back to a stranger:

> I have a problem when I know someone is going away. What if I need to get hold of them when they are away? I'll tell you what happened to me the other day when I went to the Safeway. I was in line to pay for my groceries when the woman in front of me told the cashier she is going away. All of my hearing pinpointed on exactly what she was saying. Everything else ceased to exist. My stomach became nauseous. My breath was hard to catch; it was running away from me. My heart raced. I stayed close to her. My brain started, "Maybe you should go over and ask her when she is leaving so you'll know when she is going. Or maybe you should tell her that she shouldn't go." A hundred thoughts in a matter of seconds.
>
> The good angel and the bad angel began their battle. "Well, you can't go over there, and you can't say that to her; you don't even know this lady." "Well I have to. I'm not going to know where she is, and I'm not going to know where she is going, and what if I need to talk to her while she is gone?" "Well, what would you need to talk to her about?" "Well, there is nothing. I don't know; maybe I might just need her. So I'll have to go and tell her." "Well, you can't go and tell her; you're going to look like a nut case." Back and forth. Back and forth. Back and forth. Back and forth. I couldn't get the anxiety under control. I thought I was going crazy.
>
> I watched in horror as the lady left the store. I madly thought, I'll buy these four oranges and it will be okay. No—step on that crack and it will be okay. No—pick up four twist ties and it will be okay. No—buy this, buy that; do this, do that, and it will be okay. Come up with something, come

> up with something, come up with something to combat the anxiety. What next? What next? What next? What next?
>
> I ran after her and got her license plate number. Now I know I can get hold of her if I need to. The boulder on my chest lifted, my heart slowed, and my brain stopped. I was exhausted.

It seems absurd that Leah should have to get in touch with this stranger. What could she possibly need her for? Leah recognizes the absurdity of the situation, but is still compelled to ritualize until the situation is safe. It is a one-sided relationship (with a stranger).

Leah cannot let the other person go. She has to hold that person until she feels it is safe to let them go. What compels her to hold on? I could say that OCD compels, but how could that be? OCD is just the name for a condition. OCD does not really do anything. Could it be the stranger who compels?

Van den berg (1972) would say that the stranger compels; the very woman in the grocery store is the cause. But Leah would say that that is nonsense. "How could this woman, who I don't even know, force me to do these rituals?" Well, because it is this stranger who said she was going away, and in that moment she did compel. The ritual started in that moment of the experience, while she was standing in the grocery store lineup. So it was the stranger who compelled—or was it? The answer is not so easy.

Something or someone is driving Leah to obsess after this woman, but what can it be? Leah recognizes the absurdity of the situation; otherwise she would simply comment to the woman, "Where are you going? Are you staying at such and such a place?" The woman would probably politely respond that she is

going to Las Vegas and is going to be at the Sands Hotel. Leah would then have a way to get hold of the woman, and the forcing would be over; but instead she does these crazy things like buying the right oranges, stepping on a crack, or picking up four twist ties. How could picking out and buying the right oranges relieve the anxiety that is felt when she hears the woman is going away? The ritual does not make sense; not even to Leah.

Vigilant Watch

I am always careful when I go out to check and make sure I have my purse. One day I left my purse in a restaurant, and I never got it back. There was not much money in it, but it was so difficult replacing all the cards and cancelling my credit cards. So now I always check around and under the seat I have been sitting on and actually make a habit of touching my purse to be certain I have it with me.

Gertrude has developed a ritual of closely observing stranger's actions to ensure that they have not lost or dropped something. She is vigilant of all the people around her:

> I feel responsible not only for myself, but also for everyone around me. If a stranger loses their keys, I feel it is my fault because I didn't perform my Christian duty by ensuring they were returned safely. I am not concerned that they will get sick and die. More that they will be inconvenienced and it will be my responsibility. I watch strangers carefully to make certain they don't drop their keys or leave papers behind. It is very difficult to go to a busy part of town when I have such a huge responsibility.

What happens when Gertrude *thinks* someone might have dropped keys or left some papers behind? She has to go and ask them if they have their keys or papers. In spite of their affirmative answer, she is forced to check under chairs and tables to ensure that there are no keys or papers. She may even feel the urge to check in the stranger's briefcase or bag. Despite the embarrassment of approaching complete strangers, Gertrude has to check that they have not left anything behind.

Gertrude really does not want a relationship with the strangers whom she returns to check on. There is nothing about the person that makes her want to see them again. They are not interesting, fun to be with, or enjoyable to talk to. They just happen to have perhaps dropped or not dropped their keys or papers. She does not even know them. Gertrude is forcing a relation where, really, there is not one. A relation is being born, but it is premature and not developed. In fact, the relation will die because it cannot be developed and there is nothing to support a relationship.

Do You Love Me?

I play a little game with my husband Ken. Every day I ask him, "Do you love me?" He always replies that he does love me. I respond with, "I love you more." He says, "No you don't. I love you twice as much." Then I say to him, "No, I love you more than that." Back and forth, back and forth. Ken always ends the banter by saying, "I love you to infinity, so there!" Every day we play the same silly game; always the same question and responses. Our relationship is somehow deepened because of this little "Do you love me?" game.

In the following anecdote Linda also questions love. She too repeats the same statements to her lover, yet the outcome is quite different:

> I went out with him for more than five years. I really loved him, but I started to obsess that perhaps I didn't love him. I felt compelled to confess this to him. It was the OCD telling me that I didn't love him; I know it was. I thought that if I wasn't in love with him, then I was wasting his life and hurting him, and he should go find somebody else that loves him, really loves him. So again I was afraid of hurting him. The doubt about my love for him was not rational at all. The doubt just came out of nowhere. Then one day I noticed his very best friend. We had been friends for a long time too. Suddenly the thought popped into my head that I was in love with him. So now I am telling my boyfriend, "I don't think I love you any more, but I am in love with your best friend. Maybe I love you; maybe I don't. I just don't know any more"—although I knew in my heart that I really did love him and it was my OCD talking. It is like I didn't really want to tell him that I didn't love him any more, but I had to tell him. My boyfriend finally said he couldn't handle the doubt any more, and he ended our relationship. You can only hear "I don't think I love you" so many times before you begin to doubt too. From that point on, every relationship I have been in has ended with me wondering if I am being fair to the other person. Always that sense of doubt and the need to confess. If I am alone the stress goes down and so does the OCD, but as soon as I introduce another person into my life, the stress mounts and the OCD goes wild. It is easier for me to be alone.

The first anecdote of "Do You Love Me?" describes a relationship being strengthened by continued questioning, yet in Linda's anecdote a relationship is destroyed through questioning. Why the difference? It is too easy to simply say the difference is the type of question being asked or the type of statement being

made. When you look closely at both of the stories, the same questions are being expressed. The question is one of doubt. In the first, I know of my love for Ken but playfully doubt the love of Ken for me. Questioning gives me the answer I am looking for. In Linda's anecdote she knows of the love she has for her boyfriend, but at the same time doubts her love. Rather than questioning her boyfriend, she is questioning herself. That is the nature of obsessions; they cause you to doubt the very things you believe. I also wonder, even if OCD makes Linda doubt her love for this boyfriend, why does she tell him? Why not keep those thoughts to her self? It is not that she wants to tell him. She must tell him. Something compels her to tell, to express her felt doubt.

The Voices

I have thoughts that float freely in my head. These thoughts do not really have a voice; they are just ideas in my head. I cannot even picture the thoughts because they are just there in no particular form. I can have several thoughts wandering through my head at any given time. Once in a while I pay attention to the thought and perhaps think to myself, "That is a good idea. I should write that down." Generally, the thoughts are there, but I do not pay attention to them. The thoughts do not directly affect my actions.

Last night I decided to stay at my university office to work late. It was a Sunday night, and I was pretty certain that I was alone in the building. My office is one in a long hallway of offices. To get into the hallway you have to know the secret door code, or if you are a visitor, there are a series of buzzers (like doorbells) that alert a particular person that you are there. It was about 10 pm

when someone pushed each of the buzzers, one by one. I suddenly became scared. Thoughts raced through my head. And suddenly something amazing happened. I became aware that my thoughts had become voices.

Once I gave the thoughts some attention and meaning, they became very clear voices. I had my voice of reason saying, "Don't be stupid, Mary. There is no reason to be scared"; and my other voice saying, "There is someone out there. They pushed all the buzzers to find out if anyone is in the offices." Reason spoke again: "It was just some university students fooling around. No need to be scared." Then my other voice said, "Don't be so sure. Whoever is out there, waiting by the door, wants to break in and search the offices. They are probably looking for money and laptop computers. You'd better get out of here." Reason told me, "There is nothing to be scared of. You are just as safe tonight as you were during the daytime." "Don't be so sure," shouted my other voice. I phoned my son and asked him to come to pick me up so that I could go home to a safe environment.

What is interesting is that the thoughts in my head were of no consequence until I paid attention to them. Then they came to life. The more attention I gave them, the more meaning they had. Suddenly I could actually hear voices in my head. Both voices were really me and me talking to me. It was like there was me the body, me the self of reason, and me the other self. Suddenly I understood what it meant to have voices in my head.

In the following anecdotes Leah speaks about the voices that carry on conversations in her head:

Frustration is the most predominant emotion I feel because I know that I am a perfectly sane and rational individual, so why on earth would I have to turn a tap off properly? Whoever heard of turning a tap off properly? It doesn't make sense. Yet in the moment of the ritual it is the only sense I can make of it. There is nothing logical about the rituals, and I know that. It's is not like I am fooling myself, but at the same time I know that I am. I know that I can't turn the tap off properly, and there is almost like another part of my brain that is saying, "You've got to do it right before I'll let you move on." And if I don't turn it off properly, then panic sets in and I can't make my brain think logically even though I know I am sane. Sometimes I feel almost like I have a split personality. The personalities argue back and forth. I have the sane part of my brain saying, "There is no logical reason for me to turn the tap off in a certain way; any way will suffice," but the other part of my brain says, "No, it has to be done this certain way, or some harm may come to your family, or some catastrophe may happen." Sometimes it is just "what if." The big "if" is enough to scare me into doing it properly. For me the if is unknown. If I really thought about the fear, I guess I have a fear of getting into a state where my brain is locked into that frenzied feeling and that I will never get out of that. To me it would be going crazy and never being rational again.

Even when I am aware of the steps that I have to take to stop a ritual [talking about exposure and response prevention], I have to get the approval of my brain. If my brain says, "No, I can't do that certain step," then I have to rethink it. Even if I come up with a plan, my brain can veto it. It is almost like I have to have a double signature on the plan.

I would love a break from my brain, but it doesn't happen. The logical part of my brain says, "This doesn't make sense; just move on"; but the doubt part always popping up, saying, "I can't go; I can't take the chance. I've got to do it right. There might be consequences." There are so many words coming at the same time, it is like permanently being on fast-forward. There is too much energy in the OCD brain. If you are

> travelling on a country road, people with OCD travel on an eight-lane highway. Plus we are probably travelling the wrong direction.

Leah has one part of her brain telling her to turn the tap off a certain way, but at the same time another part of her brain is telling her to just turn it off. "Any old way will suffice." Even if her brain approves a plan, another part of her brain also needs to give approval before the plan can be implemented. The logical voice says, "Move on"; but the doubt voice always interferes. "What if? What if?"

Leah is not the only person with OCD who experiences voices in her head. Many of the participants in this study had similar experiences:

> I have the OCD voice in my head. The OCD one warns me to be careful. The other one tells me to calm myself. But sometimes the one that says calm myself is not the one I want to listen to because the OCD is safer. (Anne)

> It is like my ritual talks to me, like my ritual says this or that to me. Sometimes I don't know if it's a voice or a feeling. I don't know. My voice talks to me. Occasionally they are all shouting in my head, "You've got to do it, you've got to do it, you have to." (Christy)

> OCD is like a little voice in my head. Repetitive thoughts going over and over, strong feelings of indecision going from side to side, back and forth, back and forth. It is like having an argument in my head: "Do this; no, don't do that; do this." My little voice sometimes sings; other times I sing deliberately to stop the ritual. No particular song, just whatever pops into my mind. Singing gets my mind off of the ritual. I can't count and sing at the same time. (Jane)

Anxiety with OCD makes you put the rest of your life on hold. You can't stop thinking about it. Like, if there is something on your mind, you can't let it go. You can stop for awhile, but you always have to go back. It would be nice to just walk away, but you can't. It is like, just straighten it and get it over with. It is like you give in and don't try to go against it. The one little voice says, "Go ahead. Just do it. Get it over with," or "I've got to do it." The other little voice says, "Fight it. Don't give in." I have a battle in my head. And then once I do it, I can't stop. Even though I don't want to do it, I have to do it. (Sunflower)

My anxiety ebbs and tides, but most of the time I am anxious. Even last night I was crying because I was so tired of being anxious. It is a tightness in my chest and I can't concentrate. I have this internal self-talk that will say, "It is just an obsession, you don't have to do it, don't do it, don't do it, you don't have to do it, walk away." My anxiety is always present to me; just the intensity of it changes. I don't usually experience any sweating or heart pounding, but I always feel on guard. Sometimes it is so bad I can't think. I have tried some of the antianxiety pills, but it is like putting a bandaid on the Titanic. All day I am fighting with myself, and by the time I get home I am just wiped. (Linda)

Even though I know there is nothing written on the back of the page, a little voice in my head kept telling me I better check again. The little voice in my head is like a guardian angel that is looking out for me. It is in my subconscious. The voice tells me to check the papers over and over to make sure nothing bad will happen. It says, "You'd better look at the back of the page too." Sometimes I don't accept what I have checked, and I have to do it over again. I almost feel like I'm a different person than my little voice, so I have to somehow connect back again with my little voice, and then my little voice will accept that it is okay. Sometimes I talk back to my OCD. I might say, "I am not going to check again. I have checked and

> everything is fine, and I am not going to check." When I am able to do that, I feel powerful and in control. Sometimes my little voice lets me get away without checking and rechecking. It says, "Okay, you're off the hook this time." And that is okay. (Gertrude)

Anne, Christy, Jane, Sunflower, Linda, and Gertrude all have an odd relationship with themselves. They carry on a fight within themselves. Even if they want or do not want to do something, they have to do it. Their OCD voice ensures them safety and directs their activities. They acknowledge that the OCD voice is irrational, yet they are compelled to listen to it. Listening to the voices is like a dance of pushing and pulling.

Gossiping or Must Tell?

I cannot believe what I just saw my next door neighbour doing. I saw him kissing a woman who is not his wife. Right in the middle of the restaurant, he leaned over and gave her a kiss. Imagine that! My friend, Darlene, had her back to them, or else she would have seen too. Should I tell her, or should I just keep quiet? What if this other woman is his sister or maybe a client? I do not want to be jumping to assumptions. But I just have to tell Darlene; it is too good to keep to myself.

Many years ago I worked at a psychiatric hospital in another province. A young woman was admitted to the unit on which I was working, and, like me, she was a nurse. There were many long discussions about this young nurse named Josephine, because of the nature of her illness. The psychiatrist thought she might have a rare disorder known as *obsessive compulsive disorder*. He believed this to be true because of the presentation of her symptoms. Josephine had

phoned the police to confess to murdering not one, not two, but seven student nurses. Indeed, there had been seven student nurses murdered in the previous few months at St. Paul's Hospital. Discussion centered on whether or not she had done it. If she confessed, then surely she was guilty. Why would anyone confess to something he or she had not done? The police had thought it was odd for her to confess when there was no evidence to even suspect her of these crimes. Josephine kept insisting that she could not prove her innocence; therefore, she must be guilty. It was the police who had arranged for her admission to the psychiatric unit.

During her time on the unit Josephine continued to maintain her guilt. She also began to confess to having been a part of incidents on the unit. There were Mrs. Martin's missing slippers, Mrs. Smith's missing purse, and Miss Jackson's missing book. Josephine confessed to having taken all of these items, although she could not produce them when asked. She just knew that she could not prove her innocence, so that made her guilty. It became apparent that Josephine had a need to confess. Even though she knew that what she was saying was not true, she had to tell others. She spoke about these crimes as if she were responsible.

One nurse suggested that Josephine was nothing more than a gossip—telling stories for the sake of telling them. "She probably doesn't even know she is doing it," the nurse added. Is it true that gossips are probably not aware of it when they are gossiping? Do gossips even think about what they are saying, or do they repeat things as if they were true? It seems that gossips may not reflect on what they have said to others. They do not seem to be aware that

they are gossiping. If I were to confront them for gossiping, they would probably deny that they were gossiping and say that what they were saying was true. Josephine, on the other hand, was acutely aware of what she was saying and of the force behind the telling of the stories. She had to tell. She was compelled. Josephine spent most of her time reviewing her obsessive thoughts, over and over. Her fear mounted with each intrusive thought. "I think I murdered those seven students. I must have done it. I worked at the same hospital as they did. It must have been me. I must confess."

Does a gossip feel compelled to tell? Some would say no, there is nothing forcing a gossip to tell. A gossip gossips of free will. Others would argue that anyone who has lived in a small Canadian prairie town knows a gossip has to gossip. It is his or her role in the town. He or she is compelled to gossip. So what is the difference between the telling of a gossip and the telling of a person with OCD? A gossip may be compelled to spread a story, but he or she does not resist the compulsion to tell. A person with OCD, on the other hand, tries to resist the telling. Common sense told Josephine that she could not have possibly murdered the seven student nurses, but something else told her she just might have. "I knew I hadn't murdered those students, but what if I did? I didn't want to tell the police because I knew it was ridiculous, but I had to tell. Something made me tell." She could not resist the compulsion to tell. She had to confess.

What makes gossips feel that they should repeat a piece of gossip? What makes them believe they have the right to share this information? What is it that

made Josephine feel that she must tell? What compelled her? I have to conclude that the telling of OCD is nothing like the telling of a gossip.

CHAPTER V

SEEING THE SAMENESS, IN THE DIFFERENCES OF ORDINARY RELATION AND OCD RELATION

In order to get at any truth about myself, I must
have contact with another person.
The other is indispensable to my own existence,
as well as to my knowledge about myself.
Jean-Paul Sartre

When I speak to people about OCD, they often say, "Well, I do that. Could I have OCD?" The answer is that all of us have some OCD-like behaviours. All of us have double-checked a door or jumped over the cracks in the sidewalk. Some of our behaviours are like those of someone with OCD, but not quite.

Being or Feeling Responsible?

I have my day planned out in my head. First I will go to the bank, buy a few groceries, have lunch with a friend I have not seen in ages, and finally pick up my husband from work on my way home. I am hurrying through the grocery store, running late as usual, when an elderly lady collapses right in front of me. I quickly run over to help her. She looks so little and very frightened. I speak to her softly, trying to reassure her that she will be okay, although I know from the direction her left leg is pointing that she likely has a fractured hip. I call for help. Someone phones for the ambulance. I stay with the lady, whose name I learn is Mrs. Murray. I support her head and chat. She looks so frail. I wish I could do

more to make her comfortable. When the ambulance attendants wheel her away, I feel a sigh go through my body; thank goodness I was there to help. Suddenly my thoughts turn to my friend waiting for me at the restaurant. I had better hurry.

Levinas (1985) would say that in helping Mrs. Murray I experienced "otherness." I felt her vulnerability and, in the moment, cared only for her. I completely forgot about my friend waiting for me at the restaurant. Mrs. Murray had called to me.

The word *vulnerable* comes from the Late Latin *vulnerabilis*, via Latin *vulnerare*, meaning, "that may be wounded or open to attack" (Hoad, 1986); Thompson, 1995). Levinas (1985) might say, "I am held hostage to the other. Indeed I am hostage to *my* other. I acknowledge the other to the extent that I considers myself hostage". There was nothing that I could do except help Mrs. Murray. In the moment of her vulnerability, I was held hostage. I suppose I could have turned and walked away, but it is a part of our humanism to be responsible for other people when they are in need. I had responded to her vulnerability.

When I look back to chapter 4, Anne ("Wanting to, Not Wanting to, Having to"), Leah ("In the Grocery Lineup"), and Gertrude ("Vigilant Watch") are all feeling responsible for another. Anne wants to protect her parents from a charge of murder, Leah wants to be able to get hold of the lady in the lineup who says that she is going away, and Gertrude wants to ensure that nobody loses their keys or papers. They are not responding to the vulnerability of the other; a claim has not been placed on them; the other is not holding them hostage. Rather, it seems that they are holding themselves hostage. In a very odd way they are

being forced to be responsible for another against their will. They feel an unwanted and unneeded obligation to protect or help the other. It is not on the faces of the strangers that we see the look of vulnerability, but on the faces of Anne, Leah, and Gertrude.

What would happen if Anne's parents had murdered that couple, if Leah had discovered that something had happened to the lady, or if somebody had lost their keys or papers and Gertrude did not notice? If these things had happened to the other, Anne, Leah, and Gertrude would all experience a feeling of total responsibility: "If only I had gone to dinner with them," "I should have warned her not to go away," "I should have checked more closely," "It is all my fault. I am responsible." They are somehow responsible for someone over whom they have no control. No one is putting a claim on Anne, Leah, or Gertrude; and yet they feel responsible. It is a self-imposed responsibility, not a call from someone who is vulnerable.

Desire or Want?

van Manen (2002) told a story of two lovers who questioned their love for each other. One said, "Do you love me?" The other answered, "Yes, you are my love and only love." Yet, only five minutes later one of the lovers had the desire to ask again, "Yes, but do you *really* love me?" "Yes, I really do really love you" (p. 11). van Manen's point in this story is to show the difference between *desire* and *want*. This story demonstrates the pull of desire, a desire that can never be fulfilled. The lover hears the other say, "Yes, I love you," but a few hours later asks again, "Do you love me?" They could say the same things to each other a

million times and never tire of hearing "I love you." Desire feeds on itself. The more you desire, the more you desire. Their desire can never be satisfied. If desire could be satisfied, nothing would call lovers back to each other. There would no longer be any desire. They would simply go their separate ways. But the whole point of desire is that it can never be fulfilled. To desire means an unsatisfied longing or craving (Thompson, 1995). The lovers' desire for each other is a little like an OCD ritual—something they express over and over again, where a want can be fulfilled. I want a drink so I have a glass of water. Now I am no longer thirsty. I no longer want. But desire always calls us back.

OCD is about wanting to and not wanting to do something or say something, and about wanting not to want. When I refer to Linda's anecdote of wanting to and at the same time not wanting to tell her boyfriend that she might not love him ("Do You Love Me?"), I wonder how her wanting to and not wanting to is like desire. It seems that she has an unsatisfied need to keep telling her boyfriend that she might not love him any more, but is it really a desire? Her boyfriend eventually becomes tired of her saying, "I'm not sure if I love you." Linda has the desire to keep telling him over and over, but he does not return her desire. It is a desire that only she experiences. Her desire is really more like a want, but it is not an ordinary want because an ordinary want can be fulfilled, at least temporarily. An ordinary want can be stilled. The wanting of OCD traps Linda; she is forced into saying something, over and over, that she really does not want to say. The OCD want calls her back to her boyfriend. Linda is tortured and tormented by the call of this want, where the call of desire makes our life

more pleasant, more enjoyable. Desire is what makes us sing, dance, and play. The want of OCD is sort of like desire but not really like desire.

Part of Me and Part of Me

The other day at coffee break one of the staff had brought in a box of doughnuts. The open box was sitting on the table, and a chocolate covered doughnut seemed to be calling out my name. “Come and eat me Mary. Taste my sweet chocolate topping. One doughnut won’t hurt you Mary.” “No I do not want to eat you. I have had enough sweet tasting chocolate. Leave me alone.” Even though I had resolved to start a diet, that very day, I found myself gobbling it up. I did not even taste it! In fact, I was eating it before I even realized it. A part of me ate it without me even being aware.

Leah (“The Voices”) talks about how she has to get the approval of her brain before she can commit to a plan for exposure and response prevention. Even though one part of her brain is aware of the steps to stop a ritual and is willing to attempt the treatment, another part stops her from proceeding. "If my brain says, 'No, I can't do that step,' then I have to rethink it." But just a minute, who are the two “I”s to whom Leah refers? They both seem to be a part of Leah, herself. The voice of the self is talking to the self while the self listens and tries to decide what to do. One “I” is the self as self-aware and the other “I” is the self as objectified.

Leah would love to take a break from her brain because it is so full and constantly moving. The voices in her head are forever competing, and she gets no peace. I too have had the experience of feeling overwhelmed with thoughts

and ideas rapidly bouncing around my brain, but the difference between Leah and me is that I am able to slow my thoughts and ideas down. I can literally take a break from my brain by distracting my attention. I am able to remove myself from myself. The OCD brain allows no breaks.

Anne, Christy, Jane, Sunflower, Linda, and Gertrude ("The Voices") all experience themselves as divided into parts. It is amazing that six different women experience something so similar. I want to look at each anecdote and examine each woman's experience of being divided into parts. The next six paragraphs may seem to be disjointed and perhaps they do not flow nicely, but my intent in writing them this way is to demonstrate how it feels to be divided into parts. To show how thoughts in their lives do not flow nicely, rather they are disjointed and pulling them in different directions.

Anne has one part of her warning her to be careful while the other part tells her to be calm. How can she possibly choose which to listen to? Recall a time when you were young and something had scared you. Your mother probably spoke quietly and soothingly to you, trying to calm your fear. It was an easy decision for you to choose to listen to your mother's calming voice and let the scared part of you go. Why is Anne's decision so difficult? Just go for what seems safe. But that is the problem. The OCD voice seems safer. Although a part of her wants to listen to the calming voice, the other part of her tells her that she must choose safety, and the safe thing to do is to carry out the ritual.

Christy makes an interesting comment. She says her rituals talk to her, and then she states that she is not sure if her rituals are in the form of a voice

that she hears or a feeling that she experiences. It seems the feeling may be accompanied by many voices that sometime shout at her. Christy goes on to say, "My voice talks to me." The OCD voice that she hears is her own voice. The OCD voice is not that of another, but that of her self. Christy is experiencing one part of her self, talking to another part of her self. She is listening to her own voice talk to her own voice.

Jane has a lot of counting rituals. She counts all her steps, counts each stitch when she is knitting, and counts words when reading a book. She has found that deliberately singing will distract her from the counting. What is it about singing that enables Jane to silence the OCD voice in her? How does Jane get a part of her to be quiet? Jane manages to distract her self from her self and just be quietly with her self.

Sunflower is not able to walk away from the anxiety and voices of OCD. Two voices in her head battle. To walk away from the insistent OCD voice means having to experience more anxiety. The OCD voice calls to her to perform the ritual. The only problem is that once she performs the ritual she knows she will be called back to do it again and again. Sunflower is caught in a predicament because she really does not want to listen to her OCD voice, she would prefer to fight the voice, but she knows it is easier (in the short term) to listen. Each time she gives in to the OCD voice feelings of disgust and shame follow. Giving into the OCD voice may be easier, but in many ways it makes Sunflower's life more difficult.

Linda's experience of having voices in her head all day long leaves her exhausted. Not only does she have to manage the stress of a high-pressured job, but she also has to manage the stress of parts of her arguing with each other. The OCD voice arguing with the reasonable voice causes severe anxiety and leaves her constantly feeling on guard: "When will the next obsession pop into my head? What is next? I better be prepared." The mounting anxiety from arguing with her self cannot be stilled. Linda's description of putting a bandaid on the Titanic perfectly describes how fast she is sinking and shows that no matter where she turns, there is no lifeboat.

Gertrude wonders, sometimes, if she is a different person from her OCD voice. Yet she seems to know that she is that OCD voice. It is a part of her. Gertrude's OCD voice is like a guardian angel protecting her, but it is also a huge intrusion in her day-to-day life. Her OCD voice demands her attention and bullies her into checking papers that she does not want to check. As we are with any bully, Gertrude feels powerful and in control when she can interrupt and silence the bully. The bully plays with her by saying, "You're off the hook this time." The bully gives her hope or perhaps false hope that she will always be able to connect with her "little" voice and be able to stop the ritual of checking. It is a hope that she will be able to stop that part of her that, in an odd way, also protects her.

Resisting the Must

Every day of my life I resist the temptation to do something that I feel I really want to do. I know if I give into the temptation, in the end it will not be good for me. I love cookies. I love the sweetness in my mouth and the crunch as I bite into one. I also know that if I have one cookie I will not be able to resist having another, and maybe another. By the time I have had one or two I feel that I must have another. I have totally lost my will to resist the cookies. I have given into the pull of the cookies. I always become angry with myself for not having more control, for not just saying, "No, I do not want a cookie!" Not resisting gives way to feelings of guilt, disappointment, and often shame. Sometimes I tell myself, "I will be good tomorrow." Other days I am totally able to resist having even one cookie. On those days I am proud of myself and I feel in control of my whole self.

The word *resist* has many meanings, including (a) to withstand the action or effect of, (b) to stop the course or progress of, (c) to abstain from, and (d) to strive against (Thompson, 1995). The word *must* also has many meanings. Must can mean (a) to be obliged to, (b) to be certain to, (c) ought to, or (d) to express insistence (Thompson).

Josephine ("Gossiping or Must Tell?") is in a very difficult situation. She knows that she did not kill seven nursing students, but a part of her doubts this knowing and tells her that she must confess. The doubt comes from the OCD and creates the must. The must is so strong that she cannot resist telling. So it is not that she is merely tempted to tell, but she must tell; she is obliged to tell. I cannot resist the temptation of another cookie, but she cannot resist confessing

her imagined crime. There is no temptation for Josephine. She must tell. It is a crime she insists that she committed. She is not in control of her OCD thoughts and impulses. Her OCD thoughts and impulses control her. How can Josephine possibly overcome this overpowering insistence of having to tell? It is not that she can start over fresh tomorrow. It is as if she has no will.

What is this thing we call will? What does it mean to have will? Where does our will come from? Will is defined as "the faculty by which a person decides or is regarded as deciding on and initiating action" (Thompson, 1995, p. 1603). To have will means we are able to make decisions in our life and carry out the appropriate action. Will seems to be something that is inside all of us, but sometimes it seems to be just out of our reach. Other times our will is far from our reach. Josephine does not really want to confess to the murders, it seems her will works against her.

Whereas I feel guilty for having eaten another cookie, Josephine feels guilt for not confessing her crime. She experiences guilt until she gives in to the need to confess, and I experience guilt when I give in to another cookie. Resisting the must creates guilt for Josephine, and not resisting the must creates guilt for me.

If Josephine were to resist the must, she would regain control of her thoughts and impulses. If she were to say, "I am not going to listen to my OCD voice. I am going to listen to my voice of reason," she would no longer experience the need to confess her imagined crime. But Josephine is unable to resist the must. In her mind it is best to give into the need to confess. Not resisting the must means Josephine will continue to confess to crimes she has

not committed. The next time money is missing or someone dies, Josephine will be unable to resist the must and she will confess to having stolen the money or causing the death. It is as if the must of OCD over powers her will.

CHAPTER VI

HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF CORPOREALITY?

Lived body or *corporeality* is the experience of our lived body. Sartre (1956) wrote that in health our body is passed over in silence, but in illness we become glaringly aware of our body. It is not until our body fails us that we are fully aware of the everyday functions of our body. I am not aware of my body as I walk to the corner store nor as I lift my child onto my knee, but after abdominal surgery I am clearly aware of my sore side as I stand to walk and as I reach to lift my cup of tea. It is only when it has failed me that I truly become aware of my body.

In My Head

My friend's daughter Cindy is a gold-medallist biathlete. She has competed hundreds of times, yet she always gets anxious before the race. Cindy stands poised at the starting gate and begins to ask herself, "Why am I doing this? Am I setting myself up for failure? Am I going to wet my pants?" Yet once the horn sounds and her ski poles hit the snow, the questions leave her mind and she concentrates on sliding her skis quickly through the snow. She gets into the rhythm of moving her body, mind, and skis together. Swoosh, swoosh, swoosh. Faster and faster. Seconds into the race she thinks to herself, "Go for it! You can do it!"

Leah also has times when she experiences feelings of anxiety, but her experience is not quite the same as Cindy's. Leah's feelings of anxiety are usually at a peak when she is caught in having to do a ritual and she is not able to get it just right:

> It is almost like I'm in a blender where my brain is being shook up so I can't feel anything else or sense anything else except for what is going on in my own head. I become hyperaware of my body. Actually, it is more than that. I become aware of my brain, and that is just where I am. The only place I am in my whole body is in my head. I think that is why I don't sense anything else. I'm not aware of my whole body. If I am washing my hands and they are bleeding, I don't feel the pain because the pain in my head is worse than the pain in my hands. It is just mental pain, and from the neck down I am numb. It feels like I'm crazy. If I am not in control of my brain, I am not in control of anything, so it is total fear, helplessness. It is every unwanted emotion that I can possibly feel all jammed up into one, and I feel them all the time. There is so much panic and frustration I couldn't possibly just pick out one particular emotion at any given time. It is fear, frustration, and helplessness all lumped together.

Unlike Cindy's, Leah's body and mind do not get into an easy rhythm. Instead, Leah gets caught in her anxiety. The anxiety is so intense that it does not leave her when she enters into the ritual; rather, the anxiety grows in intensity. She feels out of control. Leah washes her hands until they are bleeding, yet the physical pain does not register in her head. She is aware of only the mental pain in her head. Leah's only aim, in the moment, is to get the ritual completed correctly in hopes of the anxiety decreasing.

Making a Sandwich

If I get the thought that I am hungry, I stop what I am doing and go into the kitchen. Sometimes I know exactly what I want to eat, and other times I may peer into the fridge or cupboard, hoping that something catches my fancy. Perhaps I will have a slice of cheese and a few crackers, or maybe a fresh mango. No, nothing seems just right. "I know what I will have. I'll make myself a boiled egg and toast. That will be perfect."

For the person with OCD the experience is different. When Leah thinks that she is hungry for a ham sandwich, she goes to the fridge to get the ham:

> I open the fridge and right away my little OCD voice says, "You had better have tuna instead, because tuna has an N and an A for DAN and that is good luck." My other little voice says, "But that is nonsense. You really want a ham sandwich." The battle begins. "You have to have tuna or something will happen to the kids." I know that is silly. How can having a ham sandwich cause harm to come to my kids? "You better not take the chance. What if something happens?" Back and forth. Back and forth. Back and forth. Back and forth. It is like I am two of me. The battle in my mind is too difficult to take, so finally I reach for the tuna and make my sandwich.

Leah makes herself a tuna sandwich even though she would rather have a ham sandwich. The voice of her OCD triggers an onslaught of anxiety and does not allow her to make the choice she really wants to make. Imagine a life in which you cannot even eat what you really want? I wonder how that tuna sandwich tasted? It could not have possibly tasted "just right," but of course, according to Leah's OCD rules, it was "just right." "Just right" has a special meaning to people

with OCD. "Just right" does not mean having what you want to eat; it means having what you must eat. If Leah wants the anxiety to stop, she must eat a tuna sandwich, even if she really would prefer a ham sandwich.

Anxiety in Me

We all get anxious. I can vividly recall a time in my life when I was petrified. I was so anxious that I could not move. It was on the occasion of my first presentation at a nursing conference. For days I rehearsed my talk. In the practice sessions I was full of confidence, and I pictured myself doing very well. The day of the conference I felt a little anxious, but when I stepped up to the microphone I began to panic. I thought I was going to faint because I could not get my breath. I sped through the talk in record time. The second the presentation was over, my anxiety left. I suffered a hellish 15 minutes.

Leah vividly recalls the day her OCD started. Her anecdote is long, but I think that it needs to remain this length to demonstrate the desperation she feels:

> I was 21 years old when my OCD began. The date was January the 16th, 1984. I was out with a girlfriend at a fitness center. After working out we went out for French fries and gravy at a Chinese restaurant. We ended the evening by going to a show. I arrived home at about 11 pm. I felt fine. I prepared for bed and then lay down. Suddenly I was gripped by severe anxiety. Within minutes I had to run to the bathroom. It was like my digestive system shut down. I had diarrhoea, and my stomach was in turmoil. I could not figure out what was happening to me. I sat on the toilet, passing stool, and vomited into the bathtub. I recognized that I was afraid of something but could not identify what it was. I couldn't look in the mirror at myself. I had to totally avoid looking at the mirror because I couldn't look at myself. I got back into bed and tried to sleep thinking the whole time

how strange everything was. I would sleep for a couple of minutes and wake in a panic. Overwhelming anxiety, like something pressing on my chest. The anxiety continued all night long. The worst part wasn't the physical response of my body but the mental response. My brain was in turmoil. It was like being a hamster in one of those circular wheels, like on a treadmill that I couldn't get off. Constant and repetitive. Over and over. My brain wouldn't stop. I couldn't grab on a specific thought because there were so many thoughts going through my head at once, all interwoven with this fear. Even to this day I don't know what the fear was. I've tried to figure it out; I just can't.

I woke in the morning after sleeping two minutes at a time. It was Thursday and I knew I had to get ready for work. Even in the morning I couldn't look at myself in the mirror. I dressed and combed my hair without looking in the mirror. I left my third floor apartment and walked to catch the bus. As soon as I was on the bus the walls closed in on me. I thought, "I have to get off this bus." And then I thought, "Why do I have to get off this bus?" "I don't know; I just do." It wasn't a feeling that something was going to happen on the bus or that the bus was going to explode; it wasn't logical. There was no explanation for what this fear was. So I got off. I eventually got to work. I tried very hard to act nonchalant, that everything was okay. Physically, I looked fine; but inside, mentally, my brain was still going very fast, and my heart rate felt like it had tripled. I looked down and saw my heart pounding in my chest. It was that hard and fast.

I sat down at my desk. I tried to phone my mother. I figured that my mother could save me; she could fix whatever was wrong. She wasn't home. The feelings of panic continued to the point where I couldn't hide it any more. I talked to one of my coworkers. It was like I was losing my mind. I was afraid I was cracking up, and I didn't know how to stop it or how to get out of it. It was such a foreign feeling. I didn't know what was wrong. My coworker drove me to my mother's house. When I got there,

Mom didn't know what was wrong. I stayed like that for 72 hours. My initial panic attack lasted 72 hours.

Whereas my anxiety left as soon as the presentation was over, Leah's anxiety continued to mount. The onset of her OCD was very dramatic. I can feel the desperation, anxiety, and fear that she was experiencing. Leah was a young, level headed, intelligent, and successful businesswoman. What was happening to her life? Even her mother could not understand or explain what was happening to her daughter. Leah did not have the flu or food poisoning. She was vomiting and having diarrhoea for no obvious reason. During the time of the intense anxiety Leah lost touch with her own body. She had no control over what was happening to her as the OCD invaded and she could not understand what was happening to her. Imagine the desperate feeling of not being in control of your own body. How could Leah possibly give meaning to the anxiety she was experiencing? Leah suffered a hellish 72 hours.

Missing Parts

Have you ever woken to find that you have slept on your arm and now your arm is asleep? You can see that your arm is still attached to your body, but it does not seem to be a part of you. Your mind cannot connect with your arm. You can no longer wilfully move your arm. If you pick it up and let it go your arm drops onto the bed with a thud. A dead weight, a useless part of your body. Your sleeping arm cannot be used to push your body into a sitting position. You experience "armlessness." Sleeping on your arm causes a sensation of

armlessness, and a similar sensation is caused by anxiety. A feeling of leglessness stops Roxanne from being able to move physically past her anxiety:

> When I was in my late 20s I had an experience of panic. I was in the lounge at work and I got legless, I felt like I wasn't getting air, and I thought that I was going to collapse. I had a heady sense, with spaciness and disorientation. But the leglessness was the most profound symptom. It was a physical leglessness. I could sense my head and my body, but my legs were gone. I couldn't figure out what was wrong with me. I went to the lounge door, and the other staff told me to go home. From that point there was a whole other time of worry for me; I just kept questioning, "What is wrong with me? What if something is wrong, and what if this happens here and what if this here and what if, what if, what if?" This plaguing kind of thinking set in.

Once the blood flow returns to my deadened arm, I can once again use it. I no longer have the sensation of armlessness. Roxanne is able to walk on her legs; they are not physically deadened, but she cannot feel her legs. She experiences a profound emotional sensation of leglessness. Roxanne is forced to remain in her anxiety; she cannot walk away from it. She cannot shake her legs out and have them return to her. Roxanne's legs return to her only when the anxiety has subsided.

When Roxanne is in the anxiety, with this sense of leglessness, she also experiences plaguing thinking. The word plague(ing) is an interesting word that is defined in different ways including: (a) a contagious bacterial disease characterized by fever and delirium, (b) any severe or fatal contagious disease spreading rapidly over a wide area, (c) an unusual infestation of pests, (d) a great trouble or nuisance, (e) a curse, (f) to afflict torment, and (g) to pester or harass

continually. Plague comes to Middle English from the Latin word *plaga* meaning to stroke or wound (Thompson, 1995).

As I look at the possible definitions for the word plague(ing) I easily recognize that Roxanne is not experiencing a contagious bacterial infection because there is no evidence of fever or delirium, and although the plaguing thinking is a pest in her life it is not an infestation. Or maybe it is an infestation, because it seems she cannot get away from the thoughts. The thoughts seem to grow and spread, even reaching down into her legs. What is definitely true is that the plaguing thinking is causing Roxanne great trouble and she sees the thoughts as a great nuisance. The plaguing thinking is interfering in her day-to-day life. I do not know if it is true for Roxanne, but many people with OCD perceive OCD thoughts as a curse that torments them constantly. Indeed Roxanne views her thoughts as pestering and harassing, and the plaguing thoughts of OCD have stroked her and left her wounded.

I have thought about Roxanne's plaguing thoughts for a long time. I do not seem to find answers only more questions. Is it the plaguing, harassing thinking that drives the anxiety and causes her leglessness? Is her OCD causing the anxiety, or is her anxiety causing the OCD? Or is it both?

What if I Have a Disease?

Most nursing students, at one time or another, worry that they might have the symptoms of whatever disease is the topic of study for that week. I recall living through a period when I was convinced that I had multiple sclerosis. Every step I took was measured and calculated. Did I slip a little just then? Did my left

leg feel weaker than my right one? My vision seemed a little blurred, and I questioned my memory. I became overly conscious of my physical being. The thought of multiple sclerosis lingered in my mind. I still carried on with my life; I slept, ate, attended classes, and studied. It was just in the back of my mind and in front of my eyes, this dreaded fear of developing multiple sclerosis.

Roxanne had a dreaded fear of being diagnosed with schizophrenia. This intrusive thought was always on her mind: "What if I have schizophrenia? What will I do?"

> My predominant OCD symptom was having intrusive thoughts and images. I went through a very difficult time when I thought I might have schizophrenia. All I could see was the schizophrenia. The anxiety was always present, but generally in the background. I saw my life through the veil of anxiety. The intrusive thoughts and images would come and go, and when they got really bad, the anxiety would become more pronounced. It would be like giving me proof that I was going crazy. I had a lot of difficulty in connecting my thoughts and images to anxiety. I always thought of anxiety being related to a sense of impending doom, and I never really experienced that sense of doom. My sense was more of concern. There was a great deal of shame attached to the concern. I don't think I could have named the anxiety at the time, but now, looking back, I know.

When I close my eyes I can imagine Roxanne having these intrusive images of schizophrenia. I can almost sense her experience of living with a veil of anxiety.

Just as Roxanne lived with a veil of anxiety, I carried on with my life through a veil of multiple sclerosis. Roxanne was able to proceed with her life; it is just that the constant veil of anxiety affected how she felt and how she viewed

her life. Anxiety was always present to her; anxiety was always there to distract her.

Did you ever play dress up as kids? Remember being the bride with your crinoline draped over your head? You could still see all of your friends, but the crinoline always blurred your view a little; you were always aware of the veil. Roxanne's anxiety is like wearing a crinoline on her head, but whereas I could remove the crinoline veil, Roxanne has to constantly live with her veil.

Bump in the Road

When I hit a bump in the road, if it is a big bump, I glance into the rearview mirror to see what I hit. If it is just a little bump, I hardly notice. The thought of hitting a bump just enters and leaves my mind; it does not draw my attention.

For ordinary people, little heed is given to the thoughts flowing in and out of their minds or to the images popping into their minds. They may briefly think about jumping from a high window or may fleetingly picture themselves dying from a dreaded disease, but the thoughts and images enter and leave their mind with no consequence.

For people with OCD, similar thoughts and images become stuck in their minds, provoking great anxiety; they are unable to pass over their minds in silence. The thoughts and images are seen as intrusive and demand that the mind attend to them. Anne hits a bump in the road, and her consequent anxiety becomes a consuming fear:

> When I drive anywhere in my car I have to check and double-check that I haven't run someone over. It takes me an hour to do a ten-minute trip

> because I have to keep circling around, looking for evidence that I have run someone over. I get out of the car and walk around it, looking for any sign of blood or damage. My eyes dart around wildly, looking for a body. My heart pounds. It is so loud I can hear and feel the pounding in my own ears. My legs get weak, yet I get down on my hands and knees to look under the car. I check the ditches and nearby fields for evidence. My mind goes a million miles a second, creating "what if" stories. Overwhelming feelings of guilt consume me. I see a little pile of ice and snow on the road. Logically, I know that is what I have run over, but I still have to look for telltale signs of a serious mishap having taken place. It is only once I can prove my innocence that I am able to let go of the anxiety.

When I hit a bump in the road I pay very little attention, but as a person with OCD, Anne immediately presumes that she has run over someone with her car and is compelled to seek evidence of her guilt. Ordinary people, for a moment, may wonder if they have struck someone with their car, but when they check and there is no body, their innocence is not in doubt and the thought leaves their mind. They do not continue searching for evidence of their guilt.

Anne is not alone in her anxiety and fear of running someone over with a car. Linda has had a similar experience:

> I have the obsession about the accident that never happened. I have spent hours driving around in circles looking for dead bodies or evidence of a death. I circle around and around, over and over. Every bump in the road brings renewed doubt. After a while I don't even want to go anywhere. Driving takes too much energy and too much time. Even when I tell myself this is an obsession and I try to resist, I am exhausted by the time I get to where I am going.

Anne and Linda want to continue on with their car trip and go shopping or get to work yet something keeps drawing them back to the bump in the road. Both women want to drive on to their destination, but at the same time they want to check that they have not run over someone. They are wanting to and not wanting to check at the same time. It is a constant pull of, "Did I or didn't I? Should I or shouldn't I?" Part of their mind realizes that they did not run over anyone; there is no body, no blood, no evidence of an accident; yet another part of their mind doubts. Their thoughts control their minds rather than their minds controlling their thoughts.

Building Up and Letting Go

When I was a little girl, perhaps seven or eight years old, I was walking home from a friend's house. I had stayed longer than I was supposed to, and it was beginning to get dark outside. As I walked along the road I suddenly spotted three men standing in a group just a little into the bushes. I froze with fright. I was certain they were going to get me. I stood staring into the distance, and they stared right back at me. I couldn't move. I wanted to turn and run, but I couldn't. I don't know how long I stood on the same spot. It was my brother's voice that caught my attention: "Oh there you are. I've been looking for you." He was standing right beside the men, as if he could not see them. He stopped and motioned for me to walk toward him. Hesitantly, I took a step and then another. I kept my eyes on my brother, afraid to look at the three men in the bushes. As I got closer I glanced into the bushes. There were no men, only a big, old stump. I

felt relieved and embarrassed at the same time. I never wanted that to happen to me again.

People with OCD also have a sense of relief when their anxiety is over, but Lisa and Machiavelli experience the sense of relief a little differently than I did as a young girl. They experience relief of the obsessional thought only once the compulsion is complete. There is something about their sense of relief that draws them back so that they can once again experience that relief. In the following anecdote Machiavelli describes being drawn to a certain hair on his body:

> I have the urge to compulsively pull my own hair. I pull all of the hair on my body, but I often choose a particular hair. That hair stands out as being a bit odd. It may be thicker, darker, or straighter than other hairs. This started when I was about 14 and intensified over the following couple of years. I can vividly recall the first time I actually pulled a hair from my pubic region. I had been on vacation to Europe with my family, and on the night of our return I pulled one hair from my pubic region. That was just like taking the crack drug. I was hooked from that point on. I remember this tremendous sense of relief. It was just like a kettle blowing its lid. I pulled my hair for many years and then began to shave it off to prevent pulling. I pulled hair in the pubic area, on my scalp, on my face, inside my nose, my eyelashes, my eyebrows; in fact, there wasn't a place that hair grew that I didn't pull it. When I was 15 I was tugging at my eyebrows and one came out. It was like narcotic relief, so I began to pull more frequently. It is like I wanted to pull my hair, but at the same time I didn't want to, but I had to. It was a big quandary to me.

Lisa talks about having to pick at a particular pimple:

> When I have a build up of anxiety and it is not usually related to anything, sometimes it just comes out of the blue. My chest feels tight, my throat

> feels closed over, my heart starts to beat fast, and I just have this incredible, I call it the *urge monster*. I'm just drawn to the mirror. I take off my glasses, and I start squeezing and picking. If I can squeeze out some fluid and it sprays onto the mirror and it's gross, but if it's like a big spray, it just relaxes me so suddenly that it's almost orgasmic. That's very embarrassing, but there is this huge tension, there's this build up, and then there's this release, and that's like an orgasm. The best picking is when I can get that spray.

Drug addicts, just like Machiavelli, are in a quandary. They want to do the crack and they do not want to do the crack, and yet they have to do the crack. It is a physiological addiction that makes them have to do the crack. Is OCD also like a physical addiction?

When I was afraid of the men on the side of the road, I felt great relief when I discovered that the three men were really just a big old stump. Nothing drew me back to try to recreate that scene so that I could again experience relief. For Machiavelli and Lisa, as the anxiety builds, the urge to pull or pick increases. Once the ritual is completed there is an immediate sense of release, until the next time. They know that they will be drawn back to recreate the scenario. Is that sense of release addicting? When will the next time be? What is driving the anxiety? Is it noticing the hair that is out of place or the certain spot of skin? Or is Machiavelli actively looking for the perfect hair (which of course is the imperfect hair) to pull so he can have that high? Does the spot of skin call Lisa to the mirror, searching for that orgasm?

Think of the build up and letting go as being like pulling on a piece of elastic. As you pull, the elastic stretches and stretches. The more taut it

becomes, the tenser you feel. You experience a sense of anxiety and excitement at the same time. Suddenly you let go of one end, and there is a thrill. But what happens if, after being used over and over, the elasticity of the elastic is lost? The elastic remains stretched and limp, lifeless. The anxiety and excitement are lost. There is no sense in pulling that piece of elastic again. You need to search for another piece of elastic to regain the sense of building up and letting go.

Scuffing my Shoes

I used to get quite upset with my children for dragging the tips of their shoes in the sand when they were playing on the swing. It was a very annoying habit to me. I had just bought them new shoes, and they were scuffing them up. But of course my children were young and they did not realize what they were doing. To them they were busy experiencing the swing.

Leah has a similar experience of doing something without even knowing that it is happening:

> I can recall one particular ritual that suddenly disappeared. I used to scuff my feet together, where the balls of the feet jut out on the side. The scuffing was a ritual to prevent some unknown harm coming to someone I loved. Eventually, I would wear holes in my shoes. One time I bought a pair of turquoise blue shoes made of canvas. I thought at the time, these won't last too long, but to my surprise several months later they still looked like new shoes. I had stopped scuffing my feet together. I have no idea why the ritual stopped. It just happens from time to time. Unexplained reason. Of course I never thought that I had stopped scuffing my feet and nothing had happened to my family; I just stopped scuffing.

My children did not mind leaving their new shoes at home and wearing old runners to the park. The shoe scuffing bothered only me; the children never even noticed. Leah did not even realize that she had stopped scuffing her feet and that, surprisingly, nothing had happened to her family; but of course, nothing would happen to her family. Leah knows that her rituals do not magically make things safe in her life. It is the lingering "what if" that forces her to carry out the rituals.

Cleaning up the Kitchen

My mother taught me never to leave my house without having all of the dishes done. I usually try to clean up the kitchen before I go out, but sometimes I just cannot be bothered. I pile the dishes in the sink and think, "I'll do them when I get home. Today I am going to have fun."

The kitchen has to be cleaned up before Sunflower can leave for work in the morning. She can never just leave a mess until later:

> Things have got to be perfect. David drives the kids to school, so I have time to get the kitchen cleaned up before I go to work. It is really important to me that the placemats be put away. If I left them on the table, I'd be really tight. I couldn't just walk away and leave them. I know that if I put them away, then the nastiness will go away. Like, you don't like pain, nobody likes pain, so if you have a stomach ache you give yourself an aspirin. Why have stomach aches forever if you can get rid of the pain and you feel so good? I put the school bags in the right spot and put the placemats away, and I feel good. The nasty pain is gone.

I can think, "I am just going to leave the dishes today. I know my mother would not be happy, but what the heck? I am going to have some fun today." Sunflower

can never take the risk of leaving the placemats. She must put them away or she will be in pain all day. What is this nasty pain to which she refers?

Caught in a Vice

When a carpenter makes a rounded railing, strips of wood are stacked together and shaped into the desired curve. The strips of wood are glued and then held in place with vicelike clamps. The vice ensures that the strips of wood do not move and do not change shape. It squeezes the strips of wood holding the curve.

Imagine being caught in a vice yourself. Jane feels that she is held by a vice, but the vice does not hold her together; instead it tears her apart:

> It was more than twenty years from the appearance of my OCD symptoms until diagnosis. Anguish and mental pain were predominant. The anguish of the mental pain I experience with OCD is harder than any physical pain. It is like my head is being pounded upon, repeatedly. I feel helpless and scared. It is like being caught in a vice, and I can't get free. It is like I am locked into this squeezing and squeezing, like I am surrounded by my thoughts and am locked in and I can't stop them. When I am really bad the pain just stays and then I get suicidal, but I think mainly because I don't want to feel this way, the feeling of suicide doesn't last very long, but it is long enough to create a disturbance in my life. It is a terrible feeling to have the mental pain. It is just awful. It is very scary and very, very, very depressing. I feel so helpless. It is anguish for sure, a real mental pain.

Jane's OCD thoughts cause her a great deal of pain, but it is a pain that is not visible to those around her. Her body remains silent, yet her mind screams in

agony. Whereas the carpenter's vice holds the boards together, the vice Jane experiences pulls her apart.

Cutting My Fingers Off

My husband is missing the tip of his index finger. He accidentally cut it off with a saw when he was working as a butcher. He found that his pain was not too bad until later that night, when his finger began to throb relentlessly. Then his whole body felt the pain.

Cutting your fingers off on purpose is not an option for most people. Lisa experiences such great pain that she sees cutting her fingers off as her best option. With her fingers gone she will not be able to pick at her skin any more:

> My life has been quite a struggle. I've been to the point where I've held a butcher knife over my fingers. I've taped gloves on during the day to try to stop the picking. I've worn socks over my hands, but of course I just strip them off. Probably about four or five weeks ago I had a plan in my head where I was going to cut off the tips of my fingers. I had analgesic medication I was going to take beforehand. I was going to call the ambulance before I did it. I estimated the time it would take them to get to my house, and then I was going to chop my fingertips off. I knew that I would live; people live without the tips of their fingers. But then I knew that I would no longer be able to pick. I was really serious. I mean, being a health care professional, I knew that it would be incredibly painful; but I also knew I would just take a bunch of Tylenol 3's before I did it and hope for the best. So yeah, it's been bad.

When my husband accidentally cut off his fingertip, it caused him a great deal of pain. He had to go to the hospital for stitches and then endured many days of throbbing pain. Every time he bumped his finger he was reminded of

what had happened to him. Lisa, on the other hand, felt that she would be relieved of pain by cutting off her fingertips. Her pain is caused by the picking, so no longer being able to pick at her skin would mean no more pain. She could handle the physical throbbing pain, but her mental pain was too much to bear.

A Family Christmas

Christmastime is my favourite holiday. I love all the hustle and bustle. I love spending time with my family and friends. Getting Christmas dinner on the table for seven people can be a little stressful though. Ken, my husband, is usually able to see when I am getting stressed out, and he will lend a hand.

One Christmas Jane was stressed out, and she had all of her family coming to dinner. Her husband did not know what she was experiencing:

> The symptoms of OCD are very, very scary and depressing. I feel helpless. It is so bad I can hardly recall what it was like not to have obsessions and rituals. Anguish and mental pain are predominant. One of the worst times with my OCD was when I experienced violent thoughts one Christmas. I had the fear of harming someone. I recall thinking, "Here I am going through this torture, and everyone else is relaxed and enjoying themselves. They don't know the hell I am going through." If I had been an OCD hand washer, my family might have seen the torture I was going through; but when it is all in your head, it is hard to allow anyone in to view the pain. When it is all in your mind, it is yours alone. It didn't even show on my face.

Whereas my anxiety was visible to Ken, Jane's anxiety and pain were not visible to anyone else. Despite her horrible anxiety and mental anguish, she was left to carry on with the preparations for dinner. She never even sent any signals to

indicate that she needed help. Jane's husband did not know what she was experiencing. She endured alone.

Sleeping

I gaze at my young son as he watches a movie on television. We have always laughed about Matthew's being able to sleep anywhere. It is not too long before he is sound asleep. His breathing is so gentle and rhythmic. I see him smile in his sleep, and I know he is having a peaceful dream. He really does enjoy sleeping.

For people with OCD their world of obsessions and rituals does not always retreat, leaving them in silence. It is as if their OCD calls out to them in the sleep of the night. Leah feels lucky because although her waking hours are consumed by OCD, she often finds relief from obsessions and rituals in her sleep:

> For me OCD is a way of life. Everything I do is OCD: the way I sip my coffee, hold my cup, or set it down on the table. I've got a cup of coffee in front of me now. I'll take a sip of the coffee. Well, I will take a sip to the count of four. And if I put the coffee cup down it is on four. I have all these rituals with my husband, Dan. I have my fingers on the handle. I can take my fingers off, one, two three, four; and the last finger that I leave on the cup is my index finger, which has a D and an N in it. So you would look at me and I would sip my coffee, and I would touch my handle and take my hands off; you would never know. The only time I am able to escape from the OCD is in my sleep, although I sometimes even dream in OCD; not often though. Usually with sleep I can be totally non-OCD. I can be like a normal person.

Leah is like Matthew in that she enjoys her sleep. She has a break from the continuous counting to four and doing everything to the letters D, A, N. She can dream about not having OCD and live a life with no obsessions and compulsions.

Jane gets no relief from her OCD even when sleeping. She continues to be tormented by obsessions and rituals. She dreams about constantly writing and tearing up notes:

> I know some people get relief from their OCD when they sleep, but that is not the case for me. Even in my dreams I am writing endless lists, tearing them up, and writing them again. Some nights the lists seem to go on forever. The pieces of paper they are written on are so long they wrap around me and hold me in place. I feel like I can't move. I have a recurring dream where I tear up a list but it keeps fastening back together. I can never get it torn right. I know I moan and cry in my sleep, and I often wake up feeling anxious. There is no peace for me.

Jane is literally held in place by her dreams. She is unable to even get a sound night's sleep. She spends her day and her night obsessing and ritualizing.

Obsessions and rituals do not torment Linda during her sleep, but her dreams often trigger obsessions with which she must deal when she is awake:

> I don't dream in OCD, but I know that often my dreams will trigger OCD. I wake up obsessing about something. I have had one for a long time that I am a lesbian. I would have a dream that involved a lesbian relationship and that would trigger obsessing. I would be checking myself. I would look at other women and begin thinking "Do I like her? Am I turned on by her?" Or I would be very conscious of whether or not I was turned on by the men I saw. Thinking you might be gay is very hard on a heterosexual relationship.

Linda's dream causes her to question her own sexual orientation. She goes in search of evidence to prove that she is not a lesbian despite the fact that she really does know that she is a heterosexual. Her obsessive fear of being a lesbian grows out of something that was triggered in a dream.

CHAPTER VII

SEEING THE SAMENESS, IN THE DIFFERENCES OF ORDINARY CORPOREALITY AND OCD CORPOREALITY

The mind is its own place,
and in itself can make a Heav'n of Hell,
a Hell of Heav'n.
John Milton, Paradise Lost

All of us experience our lived bodies in different ways. Having OCD brings a new attention to one's body. People with OCD may experience many of the same bodily sensations as people without OCD, but not in quite the same way.

Feeling Anxious

Being scared is an experience we have probably all had at some time in our lives. Movies often depict a scene in which a woman is screaming and trying to run away from the man who is chasing her, or a man panicking when the "bad guy" finally confronts him. Even watching the show may cause the audience to feel scared. You might hold your breath in anticipation, bring your hands up to your face, or scream at the moment of intense startle.

Leah ("In My Head," "Making a Sandwich," "Anxiety in Me") and Roxanne ("Missing Parts," "What if I Have a Disease?") both feel scared when their anxiety gets out of control. But what they are scared about is not what most of us may fear. Leah and Roxanne are scared of what their minds and bodies are doing to

them. They are scared of the obsessions and compulsions. The fear they feel is manifested as severe anxiety, an anxiety that grips them and holds them.

Anxiety is a core aspect of OCD and might be simply defined using physiological terminology to explain the symptoms associated with it. As sympathetic and parasympathetic divisions of the central nervous system respond to a feared situation, there may be pounding of the heart, sweating, or trembling. Feelings of nonreality might accompany these symptoms.

During her moments of anxiety, Leah ("In my Head") said, "The only place I am in my whole body is in my head." The possible separation of the mind from the body is a question that has long been pondered. When Leah is caught in the anxious moment of an OCD ritual, she is only in her mind. Her physical body is no longer perceived, as if her body no longer exists. Although we might look at Leah during her hand-washing ritual and see her hands, we would not see the pain and turmoil in her mind. Leah experiences a separation of her mind and body. For the person with OCD it is not the body that is ill, but rather the mind. Is it possible that the mind, like the body, is passed over in silence when it is well and attended to only when it is ill?

When Leah ("Making a Sandwich") goes to make herself a ham sandwich her OCD voice warns her to make a tuna sandwich instead. If she had decided to make the ham sandwich, her anxiety and fear of a consequence would have been uncontrollable. It is easier to just have a tuna sandwich. Leah listens to her pending anxiety when making choices in her life. If she makes the right choice, which is the OCD choice, then there is no anxiety. If she makes the wrong

choice, she experiences severe anxiety and worries about the safety of her children. She really has no choice.

Leah ("Anxiety in Me") describes her anxiety as being like a hamster in a circular wheel. The faster the hamster runs the faster the wheel spins. Faster, faster, and faster, out of control. Really, it is like she is in a wheel that is inside another wheel. The outer wheel keeps turning as her day-to-day life continues, and the inner wheel spins like crazy. The inner wheel is going much faster than the outer wheel. She appears to others to be quite normal, but on the inside she is in turmoil. Her body and mind have become foreign to her. There is no predictability, just one thought after another interwoven with fear.

Have you ever woken abruptly from your sleep, gripped with fear? You feel in a panic, perhaps clutching your pyjama top. Your heart pounds in your chest and your breathing is rapid. It takes a few moments until you get back in touch with your thoughts and your body. Slowly you realize that you have had a bad dream. You lie back down, pull up the covers, and drift off to sleep. What would it be like to live in constant gripping fear—a fear so intense that sleep would not come?

Leah ("Anxiety in Me") cannot look in the mirror at herself, but even if she could, would she recognize herself? Leah did not understand what was happening to her as the OCD moved into her body and mind. The time of the onset of her OCD has been etched in her mind. She remembers, with great detail, the exact date that it became a part of her life. The anxiety she endured is unforgettable.

I have had the experience of nursing a woman who had her leg traumatically amputated. She would look at her missing leg and say, "I can't believe it is gone because I can still feel it there. I know I can't see it, but no kidding, I think I could get up and walk away." Later that night she had phantom pain where her missing leg had once been. She kept reaching down to rub her leg.

Roxanne ("Missing Parts") experiences a feeling of anxiety rise in her body when she is not in complete control of what is going on in her life. When Roxanne realizes that she has lost control of a part of her life, she also loses her legs. She experiences anxiety of such intensity that her legs are literally missing to her. A part of her has been lost to the anxiety. She is overwhelmed by her anxiety and cannot get herself back. Her physical body mirrors what is going on in her mind. Roxanne's body is not grounded and will not be grounded until her legs return. For Roxanne, to experience anxiety is to be legless.

Roxanne ("What if I Have a Disease?") has another experience of anxiety when she fears that she might have schizophrenia. Because she thought that anxiety was always related to a sense of impending doom, she did not recognize her anxiety for what it was; instead she believed that she was going crazy. The intrusive thoughts that popped into her head kept reinforcing the belief that she was becoming mentally ill. This in turn increased the anxiety that Roxanne could not define. She misinterpreted the anxious feeling as another sign of emerging schizophrenia. The anxiety and belief that she had schizophrenia created a

revolving cycle of more and more anxiety. At that point all of Roxanne's life was seen through a veil of anxiety.

Stuck in my Thoughts

I hate it when a song keeps playing over and over in my mind. No matter what I do, that song continues; it is stuck in my mind. Even if I have the wrong words, the tune is there: "Raindrops keep falling on my head. And just like the man whose feet are too big for his bed, nothing seems to fit. Raindrops keep falling on my head." Over and over, and then suddenly it is gone! I think to myself, "Thank goodness it stopped." And suddenly it is in my head again: "Raindrops keep falling on my head." I would love to get hold of Butch Cassidy and the Sundance Kid; then I could get them out of my mind.

Anne and Linda ("Bump in the Road") describe OCD thoughts as becoming stuck in their mind; they are not able to let go of the thoughts. They liken this "stuckness" to a sticky gearshift in a car. The car is in first gear, and as you speed up you depress the clutch to shift into second, but the gear will not change. You wiggle the shifter back and forth and push the clutch pedal in and out. Damn it, you are stuck in first gear. Wiggle, wiggle, push in and out. Wiggle, wiggle, push in and out. Finally, after wiggling and pushing for a while the shifter becomes unstuck and moves into second. With a sense of relief you depress the gas and carry on your way.

We know that people with OCD have thoughts stuck in their mind. They hang onto the thoughts and are unable to shift their thinking. Anne says that she can finally let the anxiety go when the thought is no longer stuck in her mind. She

not only hangs onto the thought, but she also hangs onto the anxiety. She is stuck with the thought and stuck with the anxiety. It seems that her mind hangs onto the obsessive thought while her body hangs onto the anxiety. Anne cannot shift her mind or her body. They are each stuck in their own space and disconnected from one another.

Linda experiences an almost identical scenario when she goes over a bump in the road. She gets stuck on the thought that she has killed someone with her car. Just as she circles around looking for bodies, her thoughts circle around and around in her mind. "I think I hit someone. I think I hit someone. I think I killed someone." "Raindrops keep falling on my head. And just like the man whose feet are too big for his bed, nothing seems to fit. Raindrops keep falling on my head."

Feeling Good

When I work very hard to write a course paper, I often feel anxious just before I hand it in to the professor. When I finally receive the grade, if I have done as well as I had hoped, I am usually quite excited. I feel so good that I could dance around the kitchen. A good mark makes me want to work hard on the next paper. I remember that good feeling, and I want to have it again.

Machiavelli ("Building Up and Letting Go") feels good when he gets a rush from pulling out the hair on his body. Lisa ("Building Up and Letting Go") feels good when she is able to get a spray out of her pimple. Machiavelli and Lisa have a more intense sensation of feeling good than I do. The pleasant feelings draw both of them back to the mirror to pull and pick some more. It is only once

the certain hair is pulled or the pimple sprays that the rush is over. Then they realize the damage that they have done to their bodies, and they feel betrayed and angry at the power of their OCD. The pleasure they receive from pulling or picking is odd, because on the one hand it feels good, but on the other hand it feels horrible. How could something that is so horrible keep pulling them back to the mirror?

Ritual or Habit?

I used to smoke cigarettes; I quit about 14 years ago. During the process of breaking the habit of smoking, it became the focus of my life. Every thought was about smoking: How long until the craving comes again? How many days, hours, or minutes has it been since I quit? I loved the smell of a freshly lit cigarette; the smell called out to me. I did not want to smoke, and at the same time I had the urge to smoke. What differed from the rituals of OCD was that I did not have the thought that I had to smoke. I knew I could control my thoughts and my habit. Stopping the habit was not about wanting to, not wanting to, and having to. Breaking the habit was about wanting to and perhaps not wanting to.

How do we know whether the rituals of OCD are not merely habits? The word *habit* comes from Middle English via Old French, from the Latin *habitus* or *habere*, which have a full range of meaning, including reference to dress and meaning to dwell (Hoad, 1986). We dwell in a habit. We live in a habit, although a habit is not always a conscious part of our awareness. The *Concise Oxford Dictionary* (Thompson, 1995) defined habit as a settled or regular tendency or

practice, a practice that is hard to give up, a mental constitution or attitude, or an automatic reaction to a specific situation.

The word *ritual*, according to the *Concise Oxford Dictionary* (Thompson, 1995), refers to the word *rite*, meaning a religious or solemn observance or act, an action or procedure required or usual in this, and a body of customary observances characteristic of a Church or a part of it. The word rite came to Middle English from the Old French *rit* or *rite* or the Latin *ritus*. Ritual is defined as a prescribed order of performing rites, a procedure regularly followed. The word ritual is derived from the Latin word *ritualis*, pertaining to rite.

We all have habits and we all take part in rituals. I always drive to the university using the same route. When there was construction on one of my usual roads, I had to detour, and it felt a little uncomfortable. There is something comforting about a habit. It leads to a sense of security and knowing. Habits lend routine to our life. Unlike the rituals of OCD, habits are not resisted. We just do them. Rituals, unlike habits, have significant meaning to us. A wedding ceremony is a ritual. Crossing oneself in a Catholic Church is a ritual. Rituals give meaning to our lives. Interestingly, both rituals and habits give us a sense of predictability.

The thought springs to mind that perhaps the breaking of habits is not only about wanting to and perhaps not wanting to. Habits can differ. Driving to work via a certain route is a habit just as using crack cocaine is a habit. When I think about an addiction to crack cocaine, breaking that habit could involve the cycle of wanting to, not wanting to, but having to. There is a physical addiction that demands more crack cocaine. Perhaps a physical addiction is more similar to a

ritual of OCD than a habit is. Despite all intentions of not using more crack cocaine, the demand of the body takes precedence over the will of the mind. For a person with OCD, despite all intentions not to wash their hands over and over, the OCD mind demands that they be washed. It is as if there is no will. What is will, and where does it come from? Is it connected to the mind, or does it combine the body and the mind? There appear to be many differences between habits and rituals.

When we break a habit we have to work at it. I have to consciously be aware that I do not want to pick up a cigarette or to have a puff of a cigarette. When I stop taking part in a ritual, I just stop. If people make the decision to leave the Catholic Church, they will no longer cross themselves, although on occasion they may catch themselves doing it out of habit. Leah ("Scuffing My Shoes") suddenly discovers that she is no longer scuffing her feet together. Some part of her has decided that she no longer needs to perform that particular ritual, and with no effort it suddenly stops. Leah becomes aware that a ritual she has been performing for many years has stopped. What is interesting about this ritual is that she was performing it without really being aware she was doing it. You could say her ritual has become a habit.

There are other ways to make a distinction between habit and ritual. We speak about having good habits or bad habits, yet we never refer to having good or bad rituals. We may recognize that someone else's ritual is different from our own, but we do not say, "That is a good ritual." In conversations we may comment that our child has picked up a bad habit. Rituals are not picked up from

other people. We pick up bad habits and good habits from other people, but rituals must be purposefully copied. Rituals must have meaning for us. The rituals of OCD are not simply habit.

Mental Anguish of OCD Pain

My friend Gail recently had a diagnosis of breast cancer. It was hard for all of her friends and family to watch her live through a radical mastectomy, chemotherapy, and radiation. A group of nurse friends got together and drew up a schedule for when each of us would help take care of Gail and her children. There were trips to the hospital, trips to hockey games and practices, and many late nights. We helped to bathe Gail when she could not wash herself. We held her up as she tired from walking. We listened to her as she spoke about getting well again and returning to her roles of wife, mother, friend, and nurse. We all shared in her pain.

People with OCD experience a pain that is not as visible as Gail's pain. They do not have a missing breast or intravenous tubes feeding into their veins. They do not need someone to bathe them or to hold them up when they tire. They suffer a mental pain—a pain that they bear alone. It is a pain others cannot see, a pain others cannot understand, and a pain few people talk about.

Sunflower ("Cleaning Up the Kitchen") describes a nastiness inside her when the kitchen is not cleaned up just right. The nastiness is a pain that cannot be medicated with pills. The only medication that will take the nastiness away is getting the ritual done right. Completing the ritual stops the anxiety. The problem with rituals being the painkiller of OCD is that they have an adverse effect by

reinforcing the obsessive thoughts and beliefs, so one has to do the rituals to decrease the pain of the anxiety. If Sunflower puts the placemats away, then she has no pain. The ritual of putting the placemats away to stop the pain is reinforced, and she will do it again tomorrow.

Pain has several meanings, including a strongly unpleasant bodily sensation such as is produced by illness, injury, or other harmful physical contact; mental suffering or distress; careful effort, trouble taken; and a troublesome person or thing. The word pain is from the Middle English via Old French *peine* from Latin *poena* meaning penalty (*Concise Oxford Dictionary,* Thompson, 1995). It is interesting that the original meaning of the word is penalty, because that is how many people with OCD experience the disorder. They see OCD as something they have to suffer with and through, almost as though they have to pay for having done something or not having done something. They feel at the mercy of others.

People with OCD experience pain in its different definitions. The rituals and obsessions of OCD can be seen as troublesome and a bother, perhaps even *a pain in the neck*, and *great pains* are taken to ensure the rituals are *painfully* correct. The pain for someone with an illness of the mind is experienced differently from the person with an illness of the body. Jane ("Caught in a Vice") shares the mental pain she endures with OCD. The pain of OCD squeezes and squeezes her, whereas the obsessions of OCD pull her in different directions. Squeezing and pulling. Squeezing and pulling. "No rest for the wicked." For what

is Jane being penalized? She has not done anything wicked or wrong; she just worries that she might have.

Just as someone with physical pain feels at the mercy of others (doctors, nurses, or drugs) for relief, Jane feels helpless. She is at the mercy of her OCD; she is alone in her pain. So often in our culture when we feel someone is making up their pain or perhaps exaggerating their pain we say, "It is all in their head." We dismiss the pain as not being real. So how do you make someone understand your pain when the pain is literally in your head?

At times the mental pain of OCD is so severe that people with the disorder contemplate ending their lives or causing physical injury. Imagine mental pain being so strong that it drives you to self-harm. Lisa ("Cutting off My Fingers"), who picks at her skin, describes the mental pain she has endured. She experiences the mental pain of OCD as more severe than the possible physical pain of cutting off her fingertips. At least the physical pain can be dealt with by taking some analgesics, but nothing ever stops the mental pain.

Jane ("A Family Christmas") has pain that no one can see, not even on her face. How is that type of pain managed? People with the pain of OCD go through that experience alone. This is not to say that people with physical pain do not suffer alone. Pain of all kinds is often endured in silence. I have often heard fellow nurses saying that they never really understood how bad pain was until they had surgery. Having gone through the experience of having an incision gave them new insights into the experience of others.

If we really listen to the experience of another, it is not necessary for us to have the same experience in order to come to an understanding of the experience. If we listen to the stories of OCD pain, we will come closer to knowing what that experience of pain is; and in knowing that experience, we will know how to help to bring some relief. Living some of the stories of OCD help us to understand the bodily experiences of the person with OCD.

Rest My Body Perchance to Dream

Many people with physical pain seek the comfort of sleep because the body is often freed of pain during sleep. Linschoten (1952) wrote, "We can only go to sleep by letting the world retreat quietly, by letting every appeal from it subside (pp. 207-264). Van den Berg (1966) added to the writings of Linschoten:

> Our falling asleep is a response to a world moving beyond our horizon and becoming silent. Only by letting things drift away from us can we fall asleep. A person who suffers from insomnia knows this only too well: the things of his existence are not silent; they scream at him and keep him aware with their loud appeal. His tossing about is a response to the daily events. Sleep is more than a physiological recovery of an outstretched biological object. Sleep means a silencing of the world. Sleep is a condition of the room, a condition of the house, a property of the creaking of an old cupboard, of the howling of the wind in the chimney, of the rustling of the trees and of the far-away bark of a dog. (pp. 106-107)

Leah ("Sleeping") does get some reprieve from her OCD when she sleeps, although not all the time. To sleep is not to have OCD, and she is able to recall what it is like to be a normal person. Sleep silences Leah's OCD. She always awakes with renewed hope for the day, but it never fails that she has to open her

eyes to the count of four. "One, two, three, four, and open. No, I didn't do that right; now I have to start over, only now I have to do it three more times to equal my lucky number four. "One, two, three, four, and open. One, two, three, four, and open. One, two, three, four, and open. Got that right." Another day begins.

Jane ("Sleeping") lives in a world where even in sleep she is not free from her OCD. Her OCD inflicts pain on her all day and all night. To be in continuous physical pain is very tiring and depressing, and it is the same for mental pain. The constant mental pain is very wearing both physically and mentally. To consistently be carrying out your life according to the obsessions and rituals causes great frustration. Imagine never getting a break from your pain. Imagine that as soon as one ritual ends another obsession rises, and a new ritual must be completed. Imagine going to sleep only to dream in obsessions and rituals.

Sleep does not silence Linda's OCD ("Sleeping"). Sleep only brings dreams that plant the seeds for other OCD thoughts and rituals that will be played out in the following days. Linda suddenly has the obsessive thought that she might be a lesbian. She is afraid to look at the people around her. She is constantly questioning her reactions to people. Her sleep has not brought the promised rest. For Linda, sleep is not a condition of the room, but rather a condition of her OCD.

Keats (1904) in his poem entitled "To Sleep," tells how sleep allows us to close our eyes and bring peace from the activities of the day, although there are nights when sleep does not come to us and we spend the night reviewing the activities of the day. When sleep does come, our body and soul rest.

O soft embalmer of the still midnight,
  Shutting with careful fingers and benign
Our gloom-pleased eyes, embowered from the light
  Enshaded in forgetfulness divine;
O soothing Sleep! if it so please thee, close
  In midst of this thine hymn, my willing eyes,
Or wait the Amen, ere thy poppy throws
  Around my bed its lulling charities;
  Then save me or the passed day will shine
Upon my pillow, breeding many woes,—
Save me from curious conscience, that still lords
  Its strength for darkness, burrowing like a mole,
Turn the key deftly in the oiled wards
  And seal the hushed casket of my soul.

But sleep does not always bring those with OCD forgetfulness divine. Despite sleep, many people with OCD are left with haunting dreams of obsessions and rituals. Even in dreams they hop over cracks in the sidewalk, wash their hands until they bleed, repeat silent prayers to seek forgiveness for having had an impure thought, buy four cans of soup instead of three to ensure that no harm comes to a loved one, and search for bodies in ditches and fields. To sleep, for some, is to endure more of the pain of OCD.

CHAPTER VIII

HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF TIME?

Lived time or *temporality* is subjective time as opposed to clock time or objective time (van Manen, 1997). Lived time is felt time or time as it is experienced in the moment. The experience of time can be shortened when you are lost in doing something you enjoy. Reading a good book can make time seem to fly. Spending time with a loving friend makes time disappear. But waiting for news of a family member in surgery can make time last forever. Your head shoots up the second there is any new movement in the room as you anticipate some news. Time drags and slows down when you are driving to visit grandparents who live in another city. "Are we almost there?" the children ask for the hundredth time in an hour. Recall your mother telling you, "A watched pot never boils"? How many times has that saying popped into your head when you are waiting for a pot of water to boil?

But is this always the case? When you are excited, time should fly by, but this is not always so. When you are waiting for a boyfriend to return from a trip, you are excited at the thought of seeing him. Does the time fly by, or does it drag on? There is an old saying that busy time goes by quickly whereas empty time goes by slowly. Lived time is how we perceive and experience it.

List Making

Cindy loves to make lists. Her mother mentions that they need to get more juice, and she will run and add it to her list. Cindy saves time by making lists because it means that she will never forget anything. She has a feeling of accomplishment as she crosses each item off as she picks it up off the shelf. When she goes shopping and comes home with everything on the list, she feels good.

Jane also makes lists. Her list making differs from Cindy's list making, however. Jane gets caught in a ritual of having to make her lists over and over:

> OCD is time consuming, and I can't begin to tell you about the energy that I lose because of obsessing. It makes me a stranger to my own body. I get caught up in list writing or skin picking, and the time just goes. I write a list and then tear it up; immediately, I rewrite the list and tear than one up too. Other times I am pulled to the mirror to examine my skin. I look, touch, and pick. I examine each and every mark on my stomach and face. I may be obsessing for what feels like five minutes, and then I glance at the clock and realize that half an hour has gone by. It is very time absorbing, which is what I hate most about this illness. It is that loss of time—time that I could be spending doing enjoyable things.

Jane becomes absorbed in her ritual and loses track of time. In the moment of the list writing or picking, she is aware of only the now. There is no past and no future. It is only once the obsessing and ritualizing are complete that Jane is able to reflect on the past. Only with reflection is she able to say, "Damn! I got caught up in the ritual, and time got away on me." In the moment of the ritual she is not able to reflect, and that is perhaps why she gets caught writing and tearing up

lists and picking her skin. She is so intent on writing or picking that what she is doing is not totally visible to her; she just knows that she has to do it. But is it true that she does not see what she is doing in the moment of the ritual?

It is interesting that Cindy's list making saves her time. She is able to do her shopping more efficiently. However, Jane's list making costs her time. Making lists and tearing them up only to rewrite them uses up Jane's time. She spends time making lists rather than spending time sewing or painting.

Good Night

When my children were little, I had a routine or ritual for saying good night to each of them. Nighttime was a fun time in our house. After their bath and a bedtime story, I would tuck each of them into their beds. I would pull up the covers under their chins and push the blankets just under them, all the way down to their feet. Then I would give them a kiss and tell them how much I loved them. I would thank them for being such an important part of my life. Every night was the same. I enjoyed spending time with each of my children during this little nighttime ritual.

Leah's anecdote, which follows, brings us into her OCD world and shows that when she is caught in the moment of the nighttime ritual, time does not exist; but once the ritual is completed correctly, time reenters her life:

> My perception of time depends on the level of anxiety I am experiencing. Sometimes time goes by very quickly, and sometimes it seems to drag. If I am trying to go to bed and I am walking through the different rooms in the house to do my final checks for the night, then I have to do little rituals each time I go through a different room or a different surface. Like, going

> on the hardwood floor, then on linoleum, and then on carpet, I have to do little rituals. I make sure that I step on certain spots on the floor and count to four each time I change surfaces. I have to be sure that I end with my left foot as I go from one surface to the other because my left side is my OCD side. It would not be done correctly if I ended with my right foot, and I would have to start over again. As I go through each room of the house I have certain spots I have to touch and certain things I have to do. When I am in my children's bedroom, I have to kiss each of them four times on their left cheek. As I lift my lips from their cheeks, I have to be certain that I am breathing in and thinking a happy thought. I have to touch every doorknob with my index finger. When I am in the hallway, I have to look in the hall mirror, smile, and concentrate on looking at my left front tooth. I step on the white spot on the carpet, and if everything has been done correctly, I can go into my bedroom. So by the time I get into my room and I get undressed and I get into bed, I will think maybe twenty minutes has passed by, and I look at the clock and it has maybe been three minutes. Yet it feels like those rituals have taken a long time. If I had to guess how long something had taken, I would usually be far off.

Leah and I both have a nighttime ritual for our children. My ritual has grown out of knowing what settles the children to bed and keeps them there. I realized that if I took the time to ensure that they were tucked in and felt safe, then they would not be getting up a hundred times for a kiss or a glass of water. Leah's nighttime ritual also ensures that her children are settled and safe, but she has an odd way of ensuring their safety. How could the time she spends doing rituals, as she moves from room to room, ensure safety? Is it time that is wasted?

The First Time

I can vaguely recall the first cigarette I smoked. It was a life-changing time for me. My years from 13 to 19 were spent sneaking around to find a good spot to smoke where my parents, of course, could not see me. It was the first time in my life that I knowingly, boldfaced lied to my mother. Whenever she mentioned smoking, I would insist that I did not smoke and ask how she could doubt my honesty. The first time I smoked, my life changed.

There is always a beginning of (to) something, whether it is the first symptoms of cancer or the start of a psychotic break. Neither cancer nor psychosis can appear suddenly out of the blue or overnight. Cancer cells begin growing within our body long before we are aware of symptoms. Brain chemistry is subtly altered before bizarre behaviours and hallucinations of psychosis become apparent. Are cancer patients and psychotic patients aware of these early changes in their body? I do not think they are. Symptoms may seem to appear out of nowhere, but in fact they have been gradually appearing. Perhaps it is the slowness with which they appear to us that makes us believe that they suddenly appear. People with cancer describe finding a lump that was not there before or a new mole on their back. It is only in retrospect that they are able to say, "For some time I have been feeling physically unwell. It was like something wasn't working smoothly in my body" or "I hadn't really paid attention to the moles on my body." People with psychosis may be able to look back over a period of their lives and recognize that there were subtle signs of a developing psychosis.

Perhaps they were not sleeping as well as usual, or maybe they were withdrawing from social activities.

People with OCD describe their OCD as coming out of the blue, or of always being there. When and where did the OCD begin? What changes were going on in the body or the mind? Linda gives us some insight into the time of onset of her OCD:

> I was attending university when it first happened. It sounds so crazy now, but at the time it was so real. I remember going home, and I had lost a cheese sandwich; I had lost my lunch. I was so worried about this that I had to retrace my steps. I went looking for my lunch, but I couldn't find it. I came home and I said, "Mom, I have got to tell you something. Something is really bothering me. I lost my lunch." The tears just came, and she knew right then that this was serious. I think at that moment she had always known something was wrong. She knew enough not to say, "Get over it! So you lost your lunch." She intuitively knew that something was very wrong. It was at that point that I really began to suffer. It was then that the OCD really began to affect my life in a lot of ways. Suddenly I wasn't able to concentrate on my studies. I would just cry and obsess over different things. Obsessions would just come into my head, and I couldn't put them out. I was always checking to see if I'd lost something. I would have to retrace my steps searching for whatever I thought I might have lost. It was very time consuming and distressing.

On reflection, Linda identifies her first symptom of OCD, but she comments that her mother had always known something was wrong. What had her mother seen? Did everything suddenly make sense to her now? Did little indicators in Linda's behaviour finally piece together? What is the experience of knowing the time of onset of an illness?

Christy feels that she was born with OCD. The symptoms of OCD have been present in her life for as long as she can remember:

> I think I was born with it. Absolutely, because I was so young. When I was just a child, people used to think it was cute. The things I used to do were so cute. I remember specifically when I was about two, I was put in the bed, and I was leaning over the side of the bed looking at my slippers on the floor. Even though my parents had taken off my slippers and put them together at the side of my bed, it wasn't good enough. I was only two! I had to lean over and I had to fiddle with them and put them just, just until I felt inside myself that they were okay. I had to have them in the right position. And then I had the feeling that everything was going to be okay because they were okay. I could stop fiddling with the slippers, but my toy closet was a bigger problem. I was continually getting boxes to be symmetrical. I'd get way back in my closet, and I'd start with the big stuff and work my way up in sizes to the smallest. But it never seemed to work out because my closet was deep. It was built into the wall and it was high up, and so the big things were *waaay* at the back, so it never worked, but that's why I was always doing it. I was always trying to get it to work out properly.

Is it possible to have OCD at the time of birth? If it is, is it really any different from being born with a cleft lip? Well, yes, it is different. Although both may be present at the time of birth, a cleft lip is there for everyone to see, whereas OCD is hidden. Parents could not look at their child and say, "Little Johnny has OCD." They may think that their child is behaving differently from other children. Parents may scratch their heads in frustration in trying to figure out why their child has to fiddle with his or her slippers. They may think the lining up of the toys is a game. Perhaps to a child the obsessions and rituals of OCD

are a game. If you get the slippers lined up just right, then you feel good, just as when you pile the blocks on top of each other and mother claps, and you feel good. The reward for your behaviour is to feel good. So even at two years of age Christy knew that she had to line the slippers up just right, but she also learned that taking time to line them up just right makes her feel good.

For Lisa, OCD began rather innocently. It slowly crept into her life and began to take up more and more of her time:

> I am 36 years old, and I believe I started to develop OCD when I was about fifteen. I started with a mild form of an eating disorder and some rituals that didn't really interrupt my life too much. I would do things like counting my steps as I walked and clicking my tongue over the retainer in my mouth that I had from having braces. I would have to do that a certain number of times before I could do something else. I would also have to kiss the ring on my finger before I could talk on the phone. I did things that didn't make sense but really didn't bother my life at all. About that time I started, as most teenagers do, squeezing at pimples. It evolved into uncontrollable urges to pick at my skin.

The onset of Lisa's OCD was liveable. She just ate what she was able to eat and avoided what she could not eat. Lisa could easily count her steps and click her tongue over the retainer. Even kissing her ring did not take a lot of time. It did not take long for bigger intrusions to enter her life, and soon she was spending many hours checking and picking her skin. OCD demanded her attention and became time consuming.

There are many first times over the course of our lives. A memorable first for me was having that first cigarette. It changed my life, although many years

later I had my last cigarette. Losing the cheese sandwich was a first-time event for Linda, straightening the shoes was a first-time event for Christy, and clicking her tongue over her retainer was a first-time event for Lisa. The time of smoking came to an end for me, but Linda, Christy, and Lisa still struggle with the time they spend on obsessing and ritualizing.

Picking

Oh! My goodness, I have a pimple on my forehead. I give it an extra little wipe with a facecloth, dab a little concealer on it, and hope no one notices. It takes no time, and I am off to work.

Lisa also has a pimple. It takes her much longer to deal with her pimple than it took for me to deal with mine:

> I usually pick at a pimple for an hour, hour and twenty minutes. There have been times where I've gone that long, gone away for half an hour, an hour, gone back for twenty minutes. Days like today where I just keep going back to it probably adds up to a total of about three hours in a day. It's a lot of wasted time, and this is what bugs me too: It's time that I could be spending cleaning my house or playing with my kids. It's wasted time. It's time that's been robbed from me, and that makes me resentful and hurt. It makes me angry.

Lisa feels frustrates that her need to pick keeps drawing her back to the mirror and demanding time. Time is not hers; it has to be shared with picking. There is a competition for time, and picking is so demanding that it usually wins. A pimple keeps Lisa in front on the mirror for a long time, whereas I spend a few seconds concealing it and carry on with my day. I do not have to compete with the pimple.

Laundry Day

Doing laundry is an everyday experience, something we all do. Sharon and Christy both do laundry once a week. Sharon, who does not have OCD, describes how she typically does her laundry:

> I have three teenagers and a husband. I hate doing the laundry, so I have some pretty strict rules. The most important rule that if it is not in the laundry basket, then it doesn't get washed. I will not waste my time trying to find dirty laundry. Monday is my designated day because I want to be sure my family has clean clothes for the week. I go from bedroom to bedroom collecting the baskets. If they have forgotten to strip their bed or throw in the pair of jeans they wore on the weekend, I just figure, too bad. Maybe next week they will remember. I take all of the baskets to the laundry room and dump them on the floor to make sorting of colours easier. Whites in one pile and colours in another. I usually wash jeans together, and I like to wash towels together. I shove a load into the washer, turn on the water, and put in the soap. I know I have about half an hour until the next load goes in, so I usually go and make beds with fresh linen or sit down with a cup of coffee. If I hear the buzzer, I go and transfer the clean load into the dryer and start the next load. I love folding the clothes when they are dry. I love the warmth and the fresh smell. I stack everyone's clothes into piles and leave them on the kitchen table for them to put away. Laundry is done for the week in about two or three hours.

Christy, who has OCD, shares her very long laundry day:

> I live by myself, but when I do laundry it is an all-day event. I start at six in the morning by gathering up the towels from the bathroom and the tea towels from the kitchen. My own personal laundry is in a hamper in my bedroom. The towels go into a green hamper, the tea towels into a blue one, and my personal laundry into a white hamper. If I accidentally put a

tea towel into the towel hamper, I get extremely distressed. I have to take the tea towel out and immediately rinse it in very hot water. Once it is rinsed I put it into a ten-percent bleach and water solution and let it soak for at least one hour. You can imagine that many of my tea towels are full of holes, but it is the only way I can stop the fear of contamination.

Once the laundry is sorted, I have to inspect every piece. I closely examine every single piece of laundry. I could spend half an hour on one sock picking all the pills off, just pick, pick, pick, pick, pick, pick, pick, pick, pick. I must have spent a year of my life just doing nothing but picking. If I leave a pill on any piece of laundry, I feel extremely uncomfortable. I have this haunting feeling that something horrible is going to happen to me. If you were to watch me picking, you may not think I felt anxious, but the anxiety I feel is overwhelming. I have to make sure everything is perfect.

At the same time as I do the picking, I also check all of the seams to ensure they are not coming apart. Sometimes I cannot trust my eyes when they say a seam is okay. I start picking at the seam, and pretty soon I have a hole. Now I have created more work for myself. Towels cause a huge problem because of the loops that get pulled. I have to cut off any of the pulled loops, and pretty soon my towels are falling apart. Try it some time. Take an old face cloth and trim the pulled loops and watch what happens. I know it is crazy, but I have to do it.

Finally, by about lunchtime I am ready to start washing. First I have to wash out the machine with a bleach solution. I have to make sure I touch every surface of the machine inside and outside. If I think I might have missed a spot, I have to start all over again. I get fresh bleach and a new rag. Of course I never have a shortage of rags because of all the towels I manage to ruin.

I very carefully lift individual items from the hamper and place them in the machine, ensuring they never touch the sides or top of the machine. If they happen to touch, then they go into a pile on the floor to be washed separately. Next I reach for the package of detergent. Every time I use the

detergent, I have to read the directions. I try not to look at it, but if I happen to notice the 1-800 phone number on the box, then I have to phone and ask the company about the safety of their product. Most importantly, I need to know if any deaths have occurred because of its usage. I know they must think I am nuts calling almost every week, but I have to call. You know, they must have call display, because now they answer their phone by saying, "Hi Christy!"

I very carefully measure out the exact amount of detergent. I often have to measure it three or four times to ensure it is correct. I carefully sprinkle the soap onto the top of the clothes, making sure there is some on each item. Then comes the difficult part of doing laundry. I have to set the dials to the correct settings. I am never certain if I have a small, medium, large, or extra-large load. I wish they would somehow mark the side of the drum. I turn the knob back and forth, back and forth, trying to decide. Finally, my OCD voice says, That will be okay; just leave it there. I used to worry about the water temperature, but now I just wash everything on cold. Then I have to decide if it is a gentle, permanent press, or regular setting I need. Even though I know my underwear should be done on gentle, I agonize over what setting to pick. I have worn out all of the knobs on my machine because of all of the twisting and turning. I keep the Maytag guy in business. Finally, I am able to close the lid and let the wash begin. But the lid doesn't stay closed for long because I have to lift it up and check that the clothes are being washed properly. I have no criteria for ensuring they are washed properly; I just have to feel right when I lift the lid. If I don't feel right, I have to start the load over again. Sometimes it can take a couple of hours to do one load.

Once the load is complete, I can move the clothes to the dryer. I know that high heat destroys the elastic in my bras, but I have to use high heat. My bras are all kind of yellow, and the elastic is breaking away, and you know what that means: I have to trim off all of the loosened elastic. My bras are dropping to pieces, and they aren't that old. I'm sure it doesn't

help that I have to wash my jeans with my bras. Anyway, I am able to just throw everything into the dryer. I turn it onto high and let it go. When the load is dry I throw it in a clean hamper. It usually takes me at least twelve hours to wash three or four loads of clothes. I carry the hamper of clean clothes upstairs and throw it in a corner. I'll deal with it tomorrow. Tomorrow is ironing day. Sometimes I think it would be easier to not do laundry. I waste so much time checking and rechecking. I hate what this OCD does to me.

Sharon and Christy both do a common household task that neither particularly enjoys doing, yet Sharon seems to derive some pleasure from the time she spends, whereas for Christy it is torture. Obsessions and compulsions interfere in doing the laundry, and Christy takes hours to do a two-hour job. Both have rules for doing the laundry, but Sharon does not have to do steps over and over. Sharon controls the washer and dryer, but the obsessions and rituals control Christy. An everyday experience for Sharon proves to be a major effort for Christy. Her time is used up on repeating actions over and over, whereas Sharon makes the best of the time to do laundry and also is free to spend time relaxing.

Starting the Day

I slept in late on Sunday morning. I heard my husband get out of bed and shower. As he left the bedroom, pulling the door closed behind him I snuggled deeper under the covers, knowing that I should get up, but not wanting to. I enjoyed the warmth of my bed and the peacefulness of my pleasant dreams. The dreams seemed so real that I did not want to leave them. I drifted from one dream to the next, hanging onto the wonderful, peaceful thoughts and images.

The phone rang, my daughter called out to her brother, and the dog barked. I was gently pulled back into the world. I rolled over and glanced at the clock. "Ten o'clock. Half the day is gone!" I jumped out of bed as if to recapture some of the hours that had slipped away.

In reality I know that lost time cannot be recaptured. When time has passed, it is gone. We talk about making up for lost time, but is that really possible? We cannot really push two hours' worth of activity into one hour. Once we have used time for some activity, no matter the activity, the time has gone. We may regret how we chose to spend the time, but what if it did not feel as if it was our choice? What if our time is wasted because we have to respond to obsessive fears with particular rituals? Sunflower expresses her frustration with the time she loses to OCD—time that could be better spent with her family:

> It is frustrating having OCD. I spend so much time checking and fixing things when I could be enjoying my family. I mean, who cares if the quilt on my bed isn't straight? Who's going to see it anyway? Just David and I. And does David care? No, of course not. Does he notice if a bed cover is straight or not? No he doesn't; it is only I.

Sunflower does not choose to straighten the quilt. Rather, she is compelled to get it straight before she can carry on with her life. Where I can choose, say, to get lost in a good novel, Sunflower has no choice but to get the quilt right. I might lose myself in a novel in spite of my intentions to read for only a few minutes and then get the dishes washed. I understand the difference between the pull of reading a good book and doing the dishes. Sunflower, on the other hand, is caught between the pull of getting a quilt straight or spending time with her

family. Whereas I have a choice of whether to read or do the dishes, Sunflower has no choice but to straighten the quilt. The choice is made by her OCD. Her time is spent doing something that takes her away from her family. The time is just used up.

Finding What I Want

I like to be organized. I find that when I am organized I save time because I know where everything is in my office. My books are arranged according to subject and alphabetically according to title. Once I tried to arrange my books by colour, but that was a disaster. I had all the red ones together and all the blue ones together, but I had a terrible time trying to find the book I wanted. I like to have everything at my fingertips. If someone asks for John Smith's book on fear, I want to be able to reach over to the correct bookshelf and pull it out. I like to be organized.

Sam also likes to have his office organized, but his plan of organization is a little like my plan of having red books and blue books together: It does not work well.

> I have a system for staying organized. Like, I file, pile, file. The last file is the most active one, and I put it in this particular spot, and then the old ones I don't use too much get moved away. Well, I don't stay in the system. Lately the worst part is I have two files open. I seem to be always losing things, although I know when I lose something it is somewhere in this room. Where in this room is the question. I start biting on the rag, just like a dog, worrying that I will not be able to find what I need. I'll go look until I can't continue looking anymore. I've decided that the amount of time I've spent looking for things I could probably have redone whatever it is I

> am looking for. Like the other day my roommate wanted some bubble wrap. I knew that I had some but couldn't remember where I had put it. So I started looking for it and he said, "No. Just forget it; close it; you don't need to look any more for it." Well, I kept thinking about it, wondering where it went. I never did find it, but I know it is in there somewhere. Well, I did find the antennae I'd lost three years ago that was misfiled in a file of home instruction manuals. Three years ago I had actually spent four full days looking for that antennae. I guess my filing system is not that great; it certainly costs me a lot of time.

Sam's system of organization actually ends up costing him time. In his attempt to be organized, he becomes disorganized. Perhaps having only one file open at a time would work, but Sam opens two files at a time. Just like having the red and blue books together did not work for me, having two files open at a time does not work for Sam. It might have been easier for Sam to go out and buy some bubble wrap or new antennae, but he feels compelled to search his files for whatever he needs. Finding the bubble wrap becomes an obsession for him. He knows it is in the room somewhere. He has to keep searching no matter how long it takes. Sam gets lost in finding what he wants.

Feeling Lumps

I felt it during my monthly check. There was no doubt in my mind that there was a lump in my left breast. I called my doctor immediately and made an appointment for the next day. Throughout the day my fingers kept finding the lump. I would suddenly notice my hand reaching for my breast. The lump was about the size of a large green pea and hard to the touch. I found myself worrying that I might have cancer. I suppose I always tend to think the worst of

worrisome situations. Time seemed to stand still for me, and I thought tomorrow would never come.

Nimi too feels a lump in her body, and then another and another. The lumps are everywhere she touches herself. She spends time touching and feeling. Here, there, and everywhere. The time she spends feeling the lumps interferes with her day-to-day life.

> I have a full-time job that is demanding of my time and energy. I have little time for obsessing, and I am always a little annoyed when the obsessive thoughts and consequent rituals sneak into my busy schedule. I had a period in my life where my ability to function normally was grossly impaired by obsessions and compulsions. I need to live each day to the fullest. I don't want to look back over my life and wish I had done things differently. I don't want to have any regrets about how I spent my time. Yet OCD sneaks up and steals my time.
>
> I sat for a month, in front of the television, watching the Gulf War evolve. During that month I did a very complete and repetitive examination of my body. I have many benign lumps all over my body. I know they are not going to kill me, yet I feel compelled to constantly feel them. I feel the lump and then I am okay for a few minutes, and then I have to feel it again. When I am checking I feel the lump and measure it with my eyes. "Has it grown? Is it firmer? Did I check that one right? I better do it again." When I am anxious I have to check and check and check and check. It can go on for hours. Sometimes the ritual of checking seems to be automatic, and it is often out of control before I am even aware that I am checking my lumps. Sometimes distracting myself from the checking will help. I try to distract myself by engaging in another activity. Perhaps I will try and do some housework or go out for lunch with a friend. Getting busy washing the dishes will help me leave the lumps alone for a while, but you know it is really hard to remove me from me. I have everything I need to

> complete the ritual right with me; it is not like I can leave the lumps behind or take the thoughts out of my mind. I am always with me. The lumps are always with me. There is no escaping from myself. Wherever I go, there I am.

I am briefly distracted from my daily activities by my lump. I stop doing the dishes to feel my lump. Nimi, though, is distracted from her lumps by doing the dishes or going out for lunch. My lump is a distraction to me, whereas Nimi's distraction is forgetting the lump for a while.

Nimi is lost in time as she checks and rechecks her lumps. A whole month passes as she obsesses over and ritualistically feels every lump on her body. Her eyes, like a ruler, measure the size of each lump as time inches away. I, on the other hand, experience time as standing still. One day feels like a month. Did one month feel like one day to Nimi? Imagine spending a whole month touching your body over and over.

CHAPTER IX

SEEING THE SAMENESS IN THE DIFFERENCES OF ORDINARY TEMPORALITY AND OCD TEMPORALITY

How long can a moment like
this belong to someone?
Gordon Lightfoot

Lived time is time as we experience it in the moment and in our day-to-day life. People with OCD do not always have the same experience of lived time, as those people who do not have the disorder.

Comfort

Comfort is something that is sought by all of us. The word *comfort* means (a) consolation, relief in affliction; (b) a state of physical well being; (c) things that make life easy or pleasant; and (d) a person who helps one. Comfort comes from the Late Latin word *confortare*, meaning to strengthen (Thompson, 1995). To comfort is to give strength or to grow strong.

When my friend Yvonne was near death, I was able to spend some time with her in the hospital. My friends and I made a funny video depicting important events in Yvonne's life. It was so good to see her laugh and enjoy herself for a few minutes; the pain that showed on her face was gone. We talked about dying and what it was like for her to have accepted death. We cried together, and

sometimes we just sat quietly holding hands. I comforted her, but she also comforted me.

Jane ("List Making") makes lists in an attempt to bring herself some comfort, but she has to tear up the lists and then write them again. Over and over. To be comfortable in one's self entails really knowing yourself, yet Jane's attempt to comfort herself makes her a stranger to her own body. The rituals of OCD are difficult to understand, even if you have OCD. If the ritual is finally completed properly, then there is a sense of relief and an odd sense of comfort in knowing that nothing bad is going to happen. It is never long though until another obsession intrudes into Jane's mind, and a ritual begins anew. This time it is to closely examine every mark on her stomach and face. Every inch of skin has to be inspected carefully. As Jane checks each spot, she is hoping to get it just right so that she can relax. Jane does not have much time to do enjoyable things that would bring peace of mind because she is too busy writing and ripping up lists or checking her stomach and skin.

Leah ("Good Night") goes through a rather lengthy ritual every night when she says good night to her children. She has very strict rules about where she steps, how she steps, her breathing, how she kisses her children, and how she looks at herself in the mirror. All of these rituals are performed in order for her to be allowed to go to her own bed. If she is not comfortable with how the rituals are done, she must start over. The number that brings Leah the most comfort is four, so that is why she does so many rituals four times. But if the ritual is not done right, she must repeat it in multiples of four. Four, 8, 12 times, until it feels just

right. It is odd that the very rituals that Leah does to bring her comfort cause her great pain.

Knowing

Is to know to believe? I know that I should not be eating ice cream if I want to lose weight, but at some level I really believe that I can eat ice cream. Another person may know not to eat ice cream and believe that it is not good for them. That belief in knowing makes it easier for them to say, "No, thanks" when ice cream is served. Our perception of knowing influences whether we believe or not.

Is to know to understand? I know that ice cream is not good for me, but do I understand the consequences of eating it? Probably not; otherwise I would say "No, thanks" when a cone is offered to me. Knowing does not necessarily mean that I understand and accept the possible consequences of my actions.

For Linda ("The First Time"), knowing the time of onset of OCD marked the beginning of ongoing obsessions and rituals, the beginning of having to search for lost items. Checking and checking, over and over, concentrating on checking and searching for lost cheese sandwiches rather than reading and studying for classes. How confusing it must be to know that you need to study, but also to know that you have to search for the lost sandwich. Why not just make yourself another sandwich? That is the dilemma for Linda. She knows that it is ridiculous to be upset over a lost sandwich, but something keeps forcing her to look for that sandwich. She may not understand why, but she knows that she has to have it, and it has to be that particular sandwich. Knowing that she had to

find her sandwich meant that she could not say "No" to the ritual. Linda had experienced her first obsession and compulsion.

Christy ("The First Time") spent time trying to get her shoes just right. She did not understand why she had to do this; she just knew that she had to. How could Christy have understood? She was only two years old. It would be very difficult to understand why Christy was upset; her parents could not have possibly known what was happening to their daughter. Her parents probably experienced that "knowing feeling" that parents get when things are not just right with their child, but simply could not put their fingers on what was not right with Christy. Her first obsession and compulsion were a very memorable moment in time.

Lisa ("The First Time") experiences her OCD creeping into her life over a period of time. There was no distinct moment of knowing she had OCD. When OCD does not interfere too much in Lisa's life, she views the obsessions and rituals as little nonsense intrusions. They were something that she had to do in order to move on to the next things in her busy schedule. She believed that by doing a specific thing she would magically have good luck and that misfortune would not befall her. And she believed that if the little nonsense intrusions worked to keep her safe, why not continue doing them? It was not long until Lisa found that she was doing more and more rituals to keep her safe. Without her even knowing, in the beginning, the obsessions and rituals had a hold on her life.

Choice

In life I do not always get to do only what I wish to do; I have other demands on my time. I do not like to clean my house; I would much rather read a book or go out for a walk. But the time usually comes where I have to clean. Generally, when I do spend time cleaning, I am very pleased with the results. I look at the mirrors and see them shining, and I feel good. I may not have spent the time doing something that I enjoy, but I feel okay about the time that I have spent cleaning.

Lisa ("Picking"), Christy ("Laundry Day"), and Sunflower ("Starting the Day") are not so ready to feel okay about how their time was spent. I may not have made my number one choice when I decided to clean my house, but it was still my choice. Lisa, Christy, and Sunflower have no choice.

The word *choice* means (a) the act or an instance of choosing, (b) a range from which to choose, and (c) the power or opportunity to choose. The word is from Middle English via Old French *chois*, from *choisir*, to choose. For people with OCD, having OCD means that there is no choice to make; the choice is always made for them. That is not really true though, because Lisa has the choice of not picking, Christy has the choice to do her laundry any old way, and Sunflower could just throw her quilt on her bed, but each of them is influenced by the feeling of "what if?" What if I do not do it the correct way and something happens to my children? What if I choose the wrong thing and I get sick? What if I cause an accident? It is always safer to go with the OCD.

Lost

One day I needed to find the publication date of an article I had referenced in a term paper. I could picture the article in my mind. I could see the title and author's name, but for the life of me I could not see the date. I started to hunt for the article. It seemed to be lost. What was I going to do? Suddenly the thought popped into my head that I should look it up on the Internet. Two minutes later I had the date. I was pleased that I had solved the problem so quickly.

Sam ("Finding What I Want") loses more than the bubble wrap and the antennae. As he searches for what he wants to find, he loses time and he loses himself. He is lost in the surroundings that are so familiar and at the same time so foreign to him. He has organized his room in a ritualized fashion, yet his organization has made it difficult for him to find what he wants. Sam is lost in the search for bubble wrap. The rest of the world is not present to him as he obsesses over the missing bubble wrap. He does not hear his roommate tell him to stop looking, and he does not stop to think that he could just buy another piece. Why does it have to be that particular piece of wrap? Why can he not just stop the search? The fear of not finding that particular piece of bubble wrap causes Sam to continue the search. He has to find the bubble wrap; he must find it.

The word *lost* is very interesting. Lost is the past and past participle of the word *lose*. The word lose is from the Old English *losian*, meaning to perish or destroy (Thompson, 1995). Sam gets so caught up in his search that he may feel as though he would perish if he were not successful in the search for the missing

bubble wrap, but we know that is not true. Sam had searched for the antennae and not found it; yet he did not perish. In the moment of the search though, Sam is frantic to find the bubble wrap, and all he can think of is perishing—perhaps even dying if he does not find it. He attaches great significance to the bubble wrap, significance that is warranted in his mind. Where I lost only time in the search for the date of an article, Sam lost time and himself in the search for the bubble wrap he needed to find.

Touch

In the morning when I wash my face, I do not use a face cloth. I prefer to cup the warm water in my bare hands and splash it onto my face. I like to feel my hands on my face. I rub my eyes and scrub my cheeks, stretching and pulling my skin. I really like the touch of my hands on my face. It is soothing and keeps me in touch with my body while at the same time helping me wake up for the day.

Nimi ("Feeling Lumps") experiences the touch of her hands on her body, but Nimi's touch is not soothing. She is constantly searching for something to have changed in her body or for something to be wrong. Checking, measuring, and feeling. Touching and doubting what she feels. Having to touch over and over. Questioning and wondering.

I look forward to touching my face with my hands, but Nimi dreads the thought of beginning to touch her lumps. I generally think of touching as bringing comfort, but for Nimi touching brings a renewed sense of concern. She wonders if the lumps have grown, hardened, or changed in any way. Touching the lumps just causes her to have to touch more. For Nimi there is no sense of comfort. She

is aware of only the lumps. Touching herself over and over has actually made her out of touch.

CHAPTER X

HOW CAN OCD BE UNDERSTOOD AS AN EXPERIENCE OF SPACE?

Spatiality is felt space, not mathematically measured space (van Manen, 1997). Lived space is where we find ourselves. We find ourselves situated in lived space, but we also find who we are in lived space. Being in a hospital emergency department or an ICU waiting room may create an atmosphere of dread and anticipation, but being in a church may cause us to reflect on our spirituality. Being in our own home allows us to be totally ourselves. Attending a ballet or a play may take us to a space where we can get away from all of our worries. Reading an excellent book may take us to an imagined space. The space where we find ourselves influences our lives and becomes a part of our lives.

Checking Over and Over

When I brought my first baby home from the hospital almost 30 years ago now, I recall being terrified that I did not know how to take care of her properly. Whenever she cried, I went through a list of checking and rechecking her, trying to figure out what she wanted. First I checked to see if she was wet, then I tried to feed her, then I tried to burp her, and then I would check to see if I had accidentally stuck her with the safety pin that was holding her diaper on. If none of those things worked to settle her down, I would start over again from the top: Is she wet, hungry, wanting to burp, or is the pin stuck in her? My frustration at not being able to make her feel better usually ended with my joining her crying. It

took several weeks for me to learn her cries and to stop going through the checklist. We were finally in the same space.

Machiavelli has similar experiences of checking. He, too, has to check and recheck what he has done. But his checking is not to ensure the well being of a baby, but rather to make his space in the world safe for him:

> When I decided to go back to university, I had excellent marks, but they came at a cost to me. I had to get up very early in the morning because it took me so long to get ready. Once I got to the university, the stress just mounted. I was always the last one out of the lab. I had to check and recheck my projects. It really bothered me that I had to write up the projects in ink; I much prefer to use pencil. Then I would get home and have to spend time rewriting the projects until they were perfect. I would also have to rewrite any of the notes I had taken during the lecture. If the professor gave us any typed notes I would have to take great care to underline any important statements. The line would have to be perfectly straight. If I couldn't draw a straight line, I had to rub it off again, rub it off again, rub it off again, until it was just right. If I didn't get it just right, there was always the possibility of something going wrong with my pets.

Machiavelli is caught in having to spend his time in the evening checking his work over and over, with the aim of getting it all just right. He has to get the space where he finds himself just right to be able to spend hours rewriting notes that most of us would just not bother doing. What drives him to this repeated rewriting and underlining? It is not that he wants to do it; it is that he must do it. If he does not do it, something bad may happen to him or his pets. What could possibly happen that would cause him to put himself through this torture? What could happen is unknown because Machiavelli always rewrites the projects,

rewrites the lecture notes, and perfectly underlines important statements. He will not take the risk of not checking and rechecking. The unknown consequences of not checking remain unknown.

Gertrude finds that if she does not pay enough attention to where she is when she is checking, she gets caught in a cycle of checking and rechecking:

> I concentrate when checking. My vision becomes centered on the piece of paper I am checking. Other objects around me are out of my focus. I know better than to get distracted. If other things in the room distract me, it means I am not concentrating on the checking and must start over again. I will check something two, four, or eight times, never three because three is an unlucky number. If I did something three times, I would have to do it one more time to make it right.

Nothing is second nature to Gertrude. Although she handles business transactions daily in her job, she cannot trust herself to casually peruse a financial statement. She must get into a space where nothing will draw her attention away from examining the statement. She must be able to give the statement her undivided attention. Gertrude checks the front of the paper and then the back. She flips the paper back and forth to ensure that she has not missed anything. Over and over. Back and forth.

Sunflower has special rules for checking and double-checking to make certain that things in her world are perfectly lined up and straight:

> When things feel just right or are just right, they are just right according to how I like it, not how you like it or think it should be. Whatever it is has to be lined up just right according to my rules. Like, the magnets on my fridge have to be lined up. I can't look at my fridge with pride; I look at it with

> hate. I absolutely hate it. I like the stuff that is there; the pictures my children have drawn are important to me. I hate it because it is imperfect, and I don't like it to be that way. I want it to be perfect. I want to have it just so. I want the magnets straight. I don't know if in other households people have things tilted? See, if I tilt this magnet I start to feel uneasy, kind of tight. I have to straighten it up. It is like I get all tense, and then the moment the magnet is in the right position, I get this sense of relief. The tension is gone. I feel good. It is like being addicted to drugs. My body is addicted to perfectionism, and so if I do things right I've given myself a shot. I've conditioned my body. I condition myself and it feels so good, but I feel disgusted with myself for having the shot. I feel disgusted with myself that I am letting this OCD rule my life. This lining up takes you over. David and the kids don't give a darn if the table is straight or not; it is just me. They don't care if a magnet is crooked. But for me everything has to be balanced; things have to be straight. Like, the two chairs must be centered. I can't just eyeball it; I have to actually center them to the table. And the table can't be a little to the left or a little to the right; it has to be centered directly under the light. It has to be in the center, can't be here or here. If someone bumps the table and it moves; I have to move it back. I couldn't just leave it. It is not that I think having the table crooked would cause any harm to my family; it just has to feel right.

Sunflower has lost control of what she would like to do in her life. She would love to have a fridge that has dozens of her children's drawings displayed on it, and she would love to have the magnets tilted any which way, but it seems that her OCD mind is in control. What is it about her OCD that demands that magnets be placed in a certain position? Sunflower does not have control over her fridge magnets. Her space is ordered by her OCD. What is just right for the OCD is not right for Sunflower; she lives in competition with herself. But she never wins,

whereas in my experience with getting into the same space as my baby, we both won.

Holding On

I have a lovely collection of spoons that have been given to me by family and friends. Every time someone goes away, I ask him or her to bring a spoon back for me. My friend Claude made a display case for my collection, and I proudly placed it on my dining room wall. Once in a while it is kind of funny because a visitor may say, "My, you have certainly travelled a lot." I do not say anything to let them in on the truth; I let them believe that I have been all over the world. I would never part with my collection of spoons because they hold many fond memories for me.

Mark D. Twain also collects things of importance to him. His things are not displayed in quite the same way as my spoons are, although he has just as many fond feelings for his collections:

> Over the years my OCD has sort of got out of control. The doctor says that I am a hoarder. I have a collection of wooden golf clubs and old tools. I also collect trunks, cases, and books. I have the books because I read to try and make myself more intelligent. The short story books will make you the most intelligent. I have lots of boxes too, but they are all special ones, not just old ones from the Safeway. I have a large collection of fossils. I don't like to give my things away, but once in a while I meet someone who really appreciates my collections, and then I can usually give them something. Sometimes I buy things that I really don't want, but I can't resist the price. That is how I got a lot of this stuff. I feel kind of silly when I look at all of this stuff. I have stuff piled from the floor to the ceiling. I have

things in my s[illegible]s garage, my mother's house and garage, and here. I could describe my home to you so you have an idea of what it looks like.

I have a one-bedroom home. You know the kind, with a bathroom right at the entrance and a kitchen just down the short hall, the main room to one side and the bedroom off that. So when you come in the door the bathroom is right there. The tub is full of boxes and things, so it is a little hard to shower. I have a sponge bath at the sink everyday. There are quite a few cases of knives and things in there too. I leave the door open to the bathroom because it won't close with the boxes of books in there. The closet, which is just across from the bathroom, is pretty full. You can see I couldn't get another thing in there. I can't reach those boxes and bags that are up top.

The hall is getting more and more crowded with boxes of collections. There is a narrow path that leads from the entrance into the kitchen and living room. I would guess that the path is maybe 18 or 20 inches in width, not wide enough for two people to pass. I use a small stool to reach the boxes that are up at the ceiling. The kitchen is tiny, and I have collections of bags and rocks in there. The counter and half the sink are where I collect my rocks for washing. The other part of the counter is used for preparing my meals. I use the other half of the sink to wash the dishes. The cupboards are where I store some of my tools. I have lots of old tools with wooden handles.

The living room and bedroom are where most of my collections are. I haven't used my bedroom in years because it is piled right to the ceiling with collections. I can't even get in there any more. I can't remember all the things that are in the bedroom. Probably there are more knives, books, and trunks. I used to have a bed, but I gave it to this guy who needed it more. I couldn't sleep on it anyway because there was so much stuff on top and underneath it. I sleep on the floor, in this little clearing in the living room. There is just enough room for me to stretch out.

> I know people are amazed when they see my home; that is why I don't invite too many in. I have my collections piled from the floor to the ceiling. Some of the collections I like to look at, but they are piled under or behind so many boxes, I can't get to them. I don't think I can get another book into the little spots left up near the ceiling, but I have enough room to do the things I want to do. I sit here on this little stool and listen to the radio, look at a book, or write on a rock. I have just enough room to walk to the kitchen and the bathroom. When I look around I guess I do have a lot of collections. I can see why the doctor says that I am a hoarder. He says I have a lot of junk. To me all of this stuff is important. I would have a hard time getting rid of it. You never know when you might need that particular knife or rock.

Mark D. Twain's description of his home gives a very vivid picture of his surroundings. Imagine having all of your living space full of collections of varying nature. What causes Mark D. Twain to have to hold on to all of his collections? What can be so important about a certain knife or box?

Both Mark D. Twain and I have a collection to which we hold on. Whereas Mark D. Twain's collection encroaches on his space, my spoon collection holds a place of honour. It is displayed in a spot where everyone can see.

Driving the Car

If I have to drive to the store, I grab my purse and keys. I glance out the door to see if I need a coat or sweater. I yell goodbye to my family, get in the car, and do up my seatbelt. I always take a moment to remind myself of how much I love the way my car feels. It has bright orange and black leather seats that heat up in the winter. I really enjoy being in my car. And then away I go.

Driving a car is not so easy for James. Every trip in his car is more like a long journey. It is a complicated and tiring ordeal. It is hard work getting the car prepared correctly to go:

> Driving the car is very difficult for me. I have many rituals that I have to complete to help combat the feelings of contamination. I pick the keys up from the little rack where I keep them. They are placed on this rack to dry because each time I use the keys I must wash them. I used to carefully dry them, but now I can let them air dry on the rack. I never used to use a wallet because of the distress it caused over having to wash everything in my wallet, including the loose change, every time I left the house. I would just wash the cards I knew I would need when I was out of the house. Now I am able to take my wallet with me without washing any of the contents. It still takes me five minutes or more to get everything into order so I am able to leave the house. Next I have to wash the outside door handle of the inner door and the inside handle of the outer door before I can leave the house. This ensures they are clean when I touch them with my clean hands. I carefully lock the doors behind me, ensuring that my coat does not brush against any part of the door. I unlock the car door, get in, sit down, and close the car door using my foot, usually my left foot. Then I wash my hands with *Wet Ones*. I wipe all the keys down one by one, and then I put the key in the ignition. I wipe my hands one more time, and then I can start the car and go. Winter driving is especially hard for me because I have to time my stops so the *Wet Ones* don't freeze. If the *Wet Ones* do freeze, it means bringing them into the house and microwaving them. So I can't stop at any one place for too long. This ritual has to be followed every time I get into the car. Once the *Wet One* is used, I simply throw it onto the floor on the passenger side. When the pile is deep I have to remove them, and that is a job I dread doing.
>
> Getting rid of the *Wet Ones* creates a mess because over a period of time I have just crumpled them up and tossed them onto the front floor

of the passenger side. The pile is often quite deep, but I can't risk having a dirty *Wet One* touch the seat. So every once in a while I have to clean up the mess. Usually I use an empty grocery bag to shove them all in and throw them away. I have to be careful not to contaminate my clothing or the car seat as I'm doing it. And if I haven't showered that day, I have to be careful not to touch the car seat. If I am wearing clean clothes, I pull up the hem of my sweater so I can touch the *Wet One* without getting the sweater dirty. Once they are all in the bag and disposed of, I have to wash my hands without getting my sweater dirty or wet. It would be easier not to use *Wet Ones*, but for the moment I really need them.

Loading the car involves at least three trips. I'll use today as an example. I went to get groceries, and I had my schoolbooks in the back seat. I have a plastic box strapped in by the lap belt so it won't fall on the floor. I've had problems with that before, books falling on the floor when I brake suddenly. I came home, opened the door, washed all the keys, and put them on the rack to dry. I washed my hands, took off my coat, and put on a sweater. I think there might have been an additional hand washing in there before I went out to the car again. Then I went out, picked up my books with my right hand, and used my left hand to open the house doors. I came in and put the books down on the table. I washed my hands again. I went out to the car again, but this time I used both hands. I hauled in the groceries. There was one bag left on the front seat. On the final trip out to the car I grabbed it with my right hand, closed the car door with my left hand, and closed the garage door with my left hand. I used the left hand to open the house door again. Then I washed my hands, took off the sweater, and I think I washed my hands again. It's going to get miserable when it gets colder this year. In the winter it takes one trip to unplug the car and open the garage door and another trip to load the books. An additional trip is needed if I have to put anything else into the car. Between each trip I have to come back in the house and wash my hands. Only then am I ready to go. I would like to just grab my books and things, go out the

> door, lock the door, open the garage doors, put my book in the back seat, unplug the car and go, but I can't do that yet. Sometimes I wish I could just go. Other times I think I'd be really filthy; then I would really spread contamination around if I did that.

Just as Mark D. Twain is holding on to his collections, James is holding on to his many rituals around driving the car. Why can he not just let go? The car is driving him rather than his driving the car. James has to constantly be aware of what he is touching; he has to keep track of what is clean and what is dirty, so that he does not spread contamination. His space in and around the car has to be perfect. Such energy goes into driving his car. When I drive my car I love the space I find myself. I can relax and enjoy the drive. James, however, gets stuck in his space. He is caught by his OCD. His space is not his alone.

Seeing is Not Believing

I look in the mirror and I see my face and my body. I recognize the lines of my face and straightness of my hair. My body is familiar to me. I know when something has changed. I smile in recognition. I trust the mirror.

Anne has a different experience of seeing herself in the mirror:

> When I look at myself in the mirror, I have to say to somebody, "Do I look okay?" I have to trust their opinion because I don't know what I look like. I don't know how to explain it, but I don't see. I don't see things. My eyes don't tell me the truth, and I have to touch and talk out loud, and that's how I can tell.

Anne is not able to recognize that the face looking back at her from the mirror is her own. She does not really know what she looks like, much less how she

appears to others. How can that be? How could she not know what she looks like? She is not blind. What does Anne see when she looks in the mirror?

Two more anecdotes from Anne show that she really does not trust her eyes. For Anne, seeing is not believing:

> I went to a movie last night, and I did my usual ritual. I don't like not being able to see the chairs. For one thing, they're folded up and it's a little bit dark in the theatre, so I always have to pull it down and look to see if there are any needles on it, and then I'll feel it with my hands. I'll be sitting like this for the first little while till I have felt everything, and only then can I relax. I'll be doing the same ritual five years from now even though I know it's not real. It doesn't matter. Even when I look at the chair and I see that there are no needles, I can't trust my eyes. I have to touch. I know I increase my chance of getting AIDS or getting stuck by a needle if there is a needle there, but I have to feel the seat. When I went last night with some friends, I spilled my pop on one of them because I was checking my seat. She said, "What are you doing?" Of course I didn't tell her.

Anne knows that there are no needles, yet she still runs her hands over the seat to check. She knows it is ridiculous, but the compulsion to check is too strong to ignore. She is caught in wanting to check, not wanting to check, but having to check.

Anne's visits to the doctor also present her with the challenge of not being able to believe her eyes:

> When I got needles during my last pregnancy or they were taking blood and stuff like that, I had to make sure I asked the nurses if the needles were brand new. I had to see with my own eyes that they were brand new. I had to watch them take it out of the package. Otherwise, what if they stuck me with an old needle? Of course I knew they would never do that,

> but at the time I believed they might. Even seeing them open the package wasn't good enough. I would have to say, "Yes, I see you opening that." Sometimes I didn't want to embarrass myself, so I would say nothing and just go home and worry about it. I might have to ask my husband, "They wouldn't do that, would they?"

What is the experience of not being able to trust your own perceptions? Perception means understanding and the intuitive recognition of truth, especially through sight (Thompson, 1995). Anne experiences worry when she is not able to double check her vision. Whereas I am able to look in the mirror and trust the image, I see that Anne does not trust the space in which she finds herself. The mirror does not show her the truth.

Getting Clean

I gather my clean clothes and put them on the bathroom counter. I adjust the water in the shower until it is nice and warm, and then I step into the shower. I always wash my hair first so the conditioner can sit in my hair while I wash the rest of my body. I've never given a lot of thought to exactly how I shower. I think I start from my shoulders and work down. I lather the soap on my skin and then rinse it off. If I am feeling a little stressed, I like to stand in the shower and let the water pound on my head. I find that soothing. My average shower is less than five minutes. It does not take much time for me to get clean.

James has a very strict ritual to follow when he showers. He can never vary the steps. The routine is always the same.

I always start my shower by washing my hands. When I wash my hands I have a sense of relief; it just feels good. It is almost like having to go to the bathroom and having to hold it in for a while and then finally getting a chance to go. I have to wash over and over until I am satisfied that I have done it right. The steps of the ritual never change. I soak my hands several times under the running water. I get a dash of liquid soap, wash, rinse; more soap, wash, rinse; more soap, wash, and rinse. I wash my hands like this, and then I go a little bit below my wrist. So that's three washes now. Despite the soreness I continue to wash. If I deviate from the routine, I have to start over again. Over and over until my mind says that it is just right and that I can stop. It is a lot of work. After I have washed my hands properly, I can move on to having a shower.

Showering is pretty complicated and takes a minimum of 25 minutes. I am a slave to habit. I shampoo my hair and then clean myself with body wash from the neck down. I have another shampoo and clean my body again. I repeat that whole process, ending with a third shampoo. I pay special attention to the groin area and the buttocks. Then I wash my legs. Finally, I have a final shampoo. And then I am done. Interestingly, when I am at my parents' I have a different ritual. I feel more dirty in my own home. I always have thoughts in my mind about how much I have been contaminated. I have to get the shower done properly.

Sometimes it is easiest to just do the showering rituals, but other times thinking about the rituals and the things that I feel I have to do is quite daunting, so I don't always shower when I should. I put it off. I have been showering following this same ritual for so many years now that I honestly do not know how to shower normally.

I find having a shower comforting and soothing. I probably wash myself in the same fashion each time I shower, but I have not really ever stopped to think about it. Showering is just something I do every day. James, though, has a very

strict ritual to which he must adhere during every shower. He can never wash his body before he has washed his hands. James cannot shower the way I do because it would not be just right. For James, having a shower is about more than just getting clean. It is about getting it just right, no matter how long it may take him.

CHAPTER XI

SEEING THE SAMENESS, IN THE DIFFERENCES OF ORDINARY EXPERIENCE OF SPATIALITY AND OCD EXPERIENCE OF SPATIALITY

Goldilocks tried Papa Bear's big bed,
but it was too hard.
Goldilocks tried Mama Bear's middle-sized bed,
but it was too soft.
Goldilocks tried Baby Bear's little bed,
and it was just right!

Lived space is experienced differently by all of us. I like to have my space neat and orderly, although at times it can become quite a mess. Before I can sit and write at my computer I must take the time to tidy up my desk. I just cannot seem to write constructively if my desk is a mess. When my space feels right I also feel right within myself. I know I am in the right space for me. I can look around with pride and a sense of joy and that is when I can really write well.

Just Right

Many of us recall the story of Goldilocks from our childhood. When Goldilocks climbed into Baby Bear's bed and it was just right, Goldilocks fell to sleep immediately. We knew what just right meant to Goldilocks; it was a feeling of safety, trust, correctness, and pleasure. Things were perfect in Goldilocks's life at that moment.

I get a great deal of pleasure out of performing a task well. I love it when a birthday cake turns out just as it is supposed to. The icing is just the right consistency, the cake is not lopsided, and it tastes great. The best part is seeing everyone enjoying a slice. But if the cake were lopsided, it would not be the end of the world. I could tell myself, "It will still taste good."

Machiavelli ("Checking Over and Over") tries to get his notes from class just right. He rewrites and checks them over and over. Although he derives no pleasure from this repeated task, it is something that must be done. Gertrude and Sunflower ("Checking Over and Over") also try to get things just right in their space. They are searching for the feelings of safety, correctness, pleasure, and trust, that just right feeling. But it comes at a great cost. For people with OCD, just right is different from what ordinary people experience. As Sunflower says, "It is all done according to her rules." Perhaps what she should be saying is that it is all done according to her OCD rules. She cannot look at her fridge with pride, only with disgust. Sunflower does not enjoy getting the magnets straight; it is just hard work. She would prefer that they were on her fridge any old way. That would give her pleasure. When the magnets are straight and the chairs lined up, she gets a feeling of safety and correctness, but not pleasure. She trusts that nothing will happen to her family because the OCD rules have been followed correctly. By doing their rituals Machiavelli and Gertrude also have a sense of safety from the consequences of not following the OCD rules.

When my cake is just right, it is something I can see as well as a feeling I experience. But for the person with OCD, just right is only felt, it is not something

that can be seen. When Machiavelli, Gertrude, and Sunflower look at what they have accomplished through continued checking there is no sense of pleasure. Sunflower can never leave a magnet tilted or a chair not in line. Gertrude must check every paper, front and back. Machiavelli can never leave a page of notes uncopied and say, "That is good enough." They always have to go for that feeling of just right. When things in their world are just right then their space is liveable.

Being in Control or Being Controlled

Most of us like to have some sense of control over our lives. I enjoy a routine and knowing what is going to happen next. I like being able to make decisions about what I am going to do and how I am going to do it. Our life carries on day after day. Holidays are always an adventure because our sense of control is lessened, but it is always nice to be home again and back to what is familiar and in our control.

There are other times when our actions are controlled by an outside force. For instance, if I am going to sew a dress, I must follow the pattern if I want the dress to turn out like the picture on the package. Or if I am going to build a house, I must get blueprints drawn up and I must follow the plans. In a sense the pattern and the blueprints are controlling my actions and dictating a small part of my space.

Mark D. Twain ("Holding On") gets caught up in collecting knives, boxes, and cases. He is so caught up in collecting and saving that he has lost control; it is as if his control has turned against him. The knives, boxes, and cases control him. He has no pattern or plan to guide his collecting. A space that was once

comfortable is now filled. How did collecting take control of Mark D. Twain? Why does he not just follow his will? There seems to be a problem with following his will. He is willing it and at the same time not willing it. He really does not want all of the boxes and cases, but something inside him tells him he had better save them, just in case. Is it that he has no will? Or that his will is too strong? Or that he cannot will his will? Mark D. Twain is collecting not because he wills to do it, but because he must do it. He is willed by something stronger than his own will (Haase, 2002). He is not in control of his collecting; his collecting is in control of him.

James ("Ready to Drive") has a similar experience to that of Mark D. Twain and he has loss of control over part of his space. James appears to be in control of driving his car because he has every step planned out before it ever happens. He knows exactly when he needs to wash, he knows when something is considered clean or dirty, and he knows he must follow the plan as laid out, or some harm will come to him or his loved ones. But something in his plan is difficult to understand.

There are traffic rules that all drivers have to follow to keep everyone on the roads safe. James has created another set of rules that he feels he has to follow to keep him safe. These rules control James's space. He knows that the rules and rituals he has developed are not logical and really will not keep him safe; however, to function on a day-to-day basis, he must follow them. He cannot help himself. He does not control his space; rather, his space controls him.

The word *control* has several meanings, including the power of directing and the power of restraining, especially self-restraint (Thompson, 1995). James has lost his power to direct how he will drive. Unlike me, he cannot simply grab the car keys and be on his way. His elaborate rules have gained power and are now in control of his driving. He cannot practice self-restraint; he dare not take the chance of not following his rules and rituals.

Trust

At times I second-guess myself. What I mean by second-guessing is that I do not trust what I have just seen or done. I measure a board and note that it is six feet long. I look at the length of board and I know that it is six feet long, yet as I turn away to pick up my saw, I start to doubt the length. Now I have to pull out the measuring tape and measure for a second time just to be doubly sure. Sure enough, it is six feet. With the reassurance of knowing the board's correct length, I can measure where I need to make the cut.

In the three anecdotes by Anne ("Seeing is Not Believing"), in an odd way she is also seeking reassurance in order to trust. She sees herself in the mirror, yet she does not know it is she. Anne cannot be certain that she looks all right without the reassuring words of another person. If her mother says, "You look nice today," Anne has to repeat, "You think I look nice today." Saying the words out loud allows her to believe her mother. The reassurance allows her to move on with her day.

Anne states that she cannot trust her own perceptions when she is in the movie theatre or at the nurse's office. She says:

> "I have to touch, have to touch. It doesn't matter what I see. With my eyes I see, but I can't remember what I see. I don't remember; that's why I have to feel with my hands. When I touch, I can remember."

Just like I was not certain about the length of the board, Anne is not sure about needles on the theatre seats, and neither is she certain that the nurse used a new needle. It is only with the second check of touching and talking out loud that she is reassured that there are no needles on the seat and that the nurse opened a clean needle. Well, perhaps it is not quite like my uncertainty of the board length. I measure the board and then doubt my measurement, so I measure it again. I use the same technique for checking as I did for the initial measurement. Anne can surely see whether there are needles on the seat and can see the nurse take a new needle out of the package. Why does she need to feel? She needs to feel because she needs a second sense (touch or speech) to support or first sense (sight). She can feel reassured only when her double check is with another sense. With reassurance her confidence in herself is restored, for the moment.

Reassurance is about learning to trust and about making one's self feel safe. Anne is desperate to feel and to be safe in her space. She assumes that her world is unsafe until she is able to get the reassurance she needs.

Ordinary

I never really give a lot of thought to what I do in my day-to-day life. I just carry on doing what I have to do. I never wonder if what I do may be strange or different from what other people do. I just assume I am ordinary, just like

everyone else. I suppose I am doing things the way I do because that is what I learned from my parents, home economics classes, and reading books. Once in a while I may notice a friend doing an activity that I do, but she is doing it a little differently from me. If I think her way of doing something is better than my way, I might change what I do. For example, I always write all of the family appointments on a calendar in the kitchen. My friend Shelley does the same thing, but she uses a different colour of ink for each family member. I thought that was a brilliant idea, so now I mark my calendar with coloured pens. I have no problem changing what I do.

James ("Getting Clean"), though, would have a great deal of difficulty changing how he showers. His obsessive fear of contamination causes him to develop complicated rituals for washing his body. OCD does not permit James to shower in an ordinary fashion; he must always follow the rituals, or something unforeseen may happen to him.

What is *ordinary*? What does it mean to be ordinary? The word ordinary means to be regular, usual, normal, or typical. It comes from the Latin word *ordinarius*, meaning orderly (Thompson, 1995). James is unable to conform to a normal shower routine. He is not able to change how he showers; he is not able to shower in a typical fashion. In fact, he has showered in a ritualized way for so long that he can no longer recall what is ordinary. He does not know how often he should shower, how many times he should lather his body with soap, or how long a shower should last. How often he showers, how many times he lathers his body, and how long his shower lasts are all dependent on OCD. I am able to

carry on activities in my life in an ordinary or typical way. I can even change the way I do things, but James must always take direction from his OCD. Being ordinary for me means not thinking, for James it means having to obsessively think. James must always be aware of his space.

Finding My Space

I have a friend who was diagnosed with diabetes over 10 years ago. He has fought the diagnosis every step of the way. He continues to eat candies, smoke, and spend hours and hours watching television. He has not accepted that he has an illness. Rather than fighting against the illness, he fights the diagnosis.

Leah, on the other hand, has accepted that she has a disorder. She recognizes that it limits her life, yet she still enjoys her life to the fullest. She has accepted the diagnosis and continues her fight against the disorder. Leah's anecdote captures this comfort zone and leaves hope for those who live within the space of OCD:

> It was 10 years before I truly believed that I needed the medications to keep my life on an even keel. I would take them for a while and then think that I could handle it on my own. I would stop the meds, and the obsessions and rituals would be terrible, so of course I would end up back on them. You would think I would finally learn. It took me ten years to realize that I really do depend on the medications. I wouldn't think of trying to treat cancer or diabetes on my own, but for some reason when the disorder is mental, I seem to think it is a personal weakness that can be treated with willpower. I now accept my OCD as a lifestyle. I have a disability, and I have come to terms with it. My life is altered, but it has not

ended. It is like being in a wheelchair. I know that I will never stand up and play basketball, so I don't even bother with that battle. I take on battles that I have a chance of winning. I battle my OCD every day in every way that I can. I live in the world that is available to me. I have one hundred percent life in my forty percent world. Before OCD the whole world out there was an opportunity to me. I could go anywhere and feel comfortable; I had every opportunity. I could walk, I could run, I could do sports, I could go to restaurants, I could do anything. There were no limitations placed on what was available to me. But now with OCD I have restrictions. There are places I can't go; there are things I can't do. I used to feel guilty about that, like if I tried a little harder, then maybe I could do it. I can't buy cards because I would have to look at the back of the card at the numbers. I would have to read every word on the card, look at all of the numbers on the card, and then I would have a hard time putting the card back on the display because I had touched it. I believe that if I touch something I have to buy it. Like when I buy cheese. If I reach for one package and accidentally touch another, I have to buy it. It doesn't matter that I don't want it. I have to buy fruit in sets of four. If I accidentally touch a fifth one, then I have to buy eight peaches. This used to stress me out until I came to terms with it; now I know that it is just my world. I cannot, no matter how hard I try, change it. Now I live within the parameters of my world; I live with my limitations. I thought, "Am I going to continuously fight this OCD or accept it and live with it? Accept that this is my world". I decided to accept that I have a forty percent world, whereas you have a hundred percent world, and you can go places and you can do things and you can go on trips, and there is not a conscious barrier there to stop you from being able to do those things. Well, that is okay now. I have my own little world, my own little circle, and how much of that am I going to enjoy? Well, I enjoy a hundred percent of that. My husband and I celebrate my OCD anniversary. When we celebrated my tenth anniversary of having OCD, we went out for supper and celebrated it. Well, the two options were

celebrate it, this is my life; or sit at home and cry over it and say, "I wish my life were different." Well, I do wish my life was different, but it is not going to be, and it's not going to change. I can wish all I want. You probably wish you were a millionaire. Well, can you change that? You can't, unless something really lucky happens. And who knows? Maybe twenty years from now something really lucky will happen and they'll find a cure. But I have to live in the here and now. To live and to have an enjoyable life with my husband and my children, I've had to accept that this is my world. And my world is smaller than your world, but I get a hundred percent enjoyment out of it. There are a lot of people out there that have a hundred percent opportunity and aren't happy. Well, I am. No regrets. This is me, and this is my life.

CHAPTER XII

CONCLUDING COMMENTS

My purpose in pursuing this hermeneutic phenomenological inquiry was to gain a deeper understanding of what it is like to live with OCD. My goal was to write a text that readers and participants would see as their own reality. I also wanted to leave other nurses and health care professionals with a richer, more thoughtful understanding of OCD. I wanted to receive the phenomenological nod of acceptance from readers and participants. Mainly, though, I wanted to give voice to all of the people who suffer with OCD and in doing so make their lives more understandable.

It has not been an easy journey for me. There have been many moments when I asked myself if I could possibly write about a topic that I had not personally experienced. I questioned my ability to write a text that could be read and understood by health care professionals, families, friends, and those with OCD. This thesis has been written and rewritten, over and over, just as van Manen (1997) promised. Phenomenology really is mainly a writing activity. I struggled over each paragraph, trying to capture the correct tone and meaning. In fact, often I struggled over each word. Many times I asked myself if another word might express the thought better or hold richer meaning. I would write pages only to delete them the next day. I wanted to get every thing "just right".

I took the almost completed thesis back to several of the participants in my study, and I also had several friends and colleagues read sections. I was

overwhelmed by the positive comments. Machiavelli read several sections and was amazed that I had been able to explain OCD so clearly. He said:

> When I am reading I can feel the pain. It is so different from any other book I have read on OCD. I feel more encouraged after reading. The writing is poetic. You bring insight to OCD through your choice of words.

Linda echoed Machiavelli's comments. She found the writing to be truthful to the experience of OCD. Linda expressed gratitude that I had undertaken this project. Christy became tearful as I read sections to her. "You are describing me; even in the stories about other people, you are describing me. OCD is so painful, and you have captured the intensity of the pain." Roxanne told me I had captured the essence of OCD. Leah said:

> It is wonderful to see someone finally delve into the true reasons behind OCD. Nothing psychological or self inflicted but truly a chemical disturbance that is uncontrollable and obsessive. Thank you for your dedicated hard work.

My nurse friends felt that they had a whole new understanding of OCD after reading the thesis. One said, "It speaks to me. I can understand how tormented these people are now. I never realised how difficult it was for them." Another said, "This is such important work. You have placed a whole new focus on OCD." Another nurse felt that she finally understood what one of her patients was experiencing: "I have new insight into the disorder."

My husband Ken said, "You have made OCD understandable to me. While I was reading I often had to stop and question myself if I did this or that; at times I felt like I had OCD." My friend Sharon said, "I never knew anyone could be so tormented by his or her own mind. It must be hell." A friend, who has OCD,

but did not take part in my study, said quite simply, "You have connected with the people with OCD." She gave me a picture of a Chinese symbol (on the next page) and explained that in Oriental culture there is a very special word that means "an opportunity to meet a person and to connect." I felt honoured to be thought of in that way.

I hope that a new understanding of the lived experience of OCD will lead to a more thoughtful practice for professionals and a renewed sense of hope for family and friends of persons with OCD. Most of all, I hope that in expressing the thoughts and feelings of all of the participants in my study, I have given them a voice that will be heard. I have outlined a plan to disseminate my research findings through presentations, articles, and by forming a support group, all of which are an important part of any study (Appendix G).

I acknowledge that another researcher could take these same stories and have a different interpretation of them; therefore, I also acknowledge that the findings of this study are not generalizable to a whole population. The anecdotes in the preceding chapters provide only a small glimpse into the lived experience of OCD and do not provide final answers to any question. My writings are only a small part of the experience. Although I have been able to provide a glimpse into the lived experience of OCD I know that in another time and another space I also may interpret these same stories with new and different insights. This research is by no means complete. Many questions remain. The questions call out to be recognized, discussed, and explored by perhaps another researcher or myself. My research into the lived experience of OCD is not yet quite "just right".

REFERENCES

Abramowitz, J. S., Foa, E. B., & Franklin, M. E. (2003). Exposure and ritual prevention for obsessive compulsive disorder: Effects of intensive versus twice-weekly sessions. *Journal of Consulting & Clinical Psychology, 71*(2), 394-398.

Alevizos, B., Lykouras, L., Zervas, I. M., & Christodoulou, G. N. (2002). Risperidone-induced obsessive compulsive symptoms: A series of six cases. *Journal of Clinical Psychopharmacology, 22*(5), 461-467.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Anderson, J. M. (1989). The phenomenological perspective. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 15-26). Rockville, MD: Aspen.

Antony, M. M., Downie, F., & Swinson, R. P. (1998). Diagnostic issues and epidemiology in obsessive-compulsive disorder. In R. P. Swinson, M. M. Antony, S. Rachman, & M. A. Richter (Eds.), *Obsessive-compulsive disorder: Theory, research, and treatment* (pp. 3-32). New York: Guilford.

Apter, A., Fallon, M., King, R., Rataoni, G. Z. A., Binder, M., Weizman, A., et al. (1996). Obsessive compulsive characteristics: From symptoms to syndrome. *Journal of American Academy of Child and Adolescent Psychiatry, 35*(7), 907-912.

Baer, L. (1996). Behaviour therapy: Endogenous serotonin therapy? *Journal of Clinical Psychiatry, 57*(Suppl. 6), 33-35.

Baer, L., & Greist, J. (1997). An interactive computer-administered self-assessment and self-help program for behaviour therapy. *Journal of Clinical Psychiatry, 58*(Suppl. 12), 23-28.

Baer, L., & Minichiello, W. E. (1998). Behaviour therapy for obsessive-compulsive disorder. In M. A. Jenike, L. Baer, & W. E. Minichiello (Eds.), *Obsessive-compulsive disorders: Practical management* (pp. 337-367). New York: Mosby.

Bailey, P. (1997). Finding your way around qualitative methods in nursing research. *Journal of Advanced Nursing, 25*, 18-22.

Barlow, D. H. (2002). *Anxiety and its disorders* (2nd ed.). New York: Guilford.

Bebbington, P. E. (1998). Epidemiology of obsessive-compulsive disorder. *British Journal of Psychiatry, 173*(Suppl. 35), 2-6.

Beck, A. T. (1976). *Cognitive therapy and the emotional disorders*. Boston: Meridian.

Beck, A. T., Emery, G., & Greenberg, R. L. (1985). *Anxiety disorders and phobias: A cognitive perspective*. New York: Basic Books.

Beck, J. S. (1995). *Cognitive therapy: Basics and beyond*. New York: Guilford Press.

Bergqvist, P., Bouchard, C., & Blier, P. (1999). Effect of long-term administration of antidepressant treatments on serotonin release in brain regions involved in obsessive-compulsive disorder. *Biological Psychiatry, 45*, 164-174.

Bergum, V. (1991). Being a phenomenological researcher. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 55-71). London, ON: Sage.

Bergum, V. (1998). Relational ethics. What is it? *In Touch: Provincial Health Ethics Network, 1*(2), 1-3.

Black, D. W., & Blum, N. S. (1992). Obsessive-compulsive disorder support groups: The Iowa model. *Comprehensive Psychiatry, 33*, 65-71.

Boswell, J. (1979). *The life of Samuel Johnson*. Markham, ON: Penguin. (Original work published in 1791)

Bouchard, C., Rheaume, J., & Ladouceur, R. (1999). Responsibility and perfectionism in OCD: An experimental study. *Behaviour Research and Therapy, 37*, 239-248.

Byrne, T. P. (1989). Letter to the editor. *Scientific American, 260*, 11-12.

Califano, J. (1996, June). The perils of perfectionism. *American Health*, pp. 72-75.

Callner, J. (1995). Solutions: My life began again. *Journal of the California Alliance for the Mentally Ill, 6*(1), 48-49.

Cannon, W. (1929). *Bodily changes in pain, hunger, fear, and rage* (2nd ed.). New York: Appleton-Century-Crofts.

Case, C. (1995). Obsessive-compulsive disorder and spirituality. *Journal of the California Alliance for the Mentally Ill, 6*(1), 45-46.

Clark, D., & Purdon, C. (1995). The assessment of unwanted intrusive thoughts: A review and critique of the literature. *Behaviour Research and Therapy, 33*(8), 967-976.

Cowles, K. V. (1988). Issues in qualitative research on sensitive topics. *Western Journal of Nursing Research, 10*(2), 163-179.

Creamer, M. (1987). Cognitive interventions in the treatment of obsessive-compulsive disorders. *Behaviour Change, 4*(1), 20-27.

Cross, C. A., & Hansen, N. E. (2000). Clarifying the experience of shame: The role of attachment style, gender, and investment in relatedness. *Personality and Individual Differences, 28,* 897-907.

Dar, R., & Greist, J. (1992). Behaviour therapy for obsessive compulsive disorder. *Psychiatric Clinics of North America, 15*(4), 885-893.

Darwin, C. R. (1872). *The expression of the emotions in man and animals.* London: John Murray.

De Silva, P., & Rachman, S. (1998). *Obsessive-compulsive disorder: The facts* (2nd ed.). Oxford: Oxford University Press.

Delgado, P., & Moreno, F. (1998). Different roles for serotonin in anti-obsessional drug action and the pathophysiology of obsessive-compulsive disorder. *British Journal of Psychiatry, 173*(Suppl. 35), 21-25.

Demal, U., Lenz, G., Mayrhofer, A., Zapotoczky, H. G., & Zitterl. W. (1993). Obsessive-compulsive disorder and depression. A retrospective study on course and interaction. *Psychopathology, 26*(3-4), 145-150.

Denys, D., van Megen, H., & Westenberg, H. (2002). Quetiapine addition to serotonin reuptake inhibitor treatment in patients with treatment-refractory obsessive compulsive disorder: An open-label study. *Journal of Clinical Psychiatry, 63*(8), 700-703.

Dougherty, D. D., Baer, L., Cosgrove, G. R., Cassem, E. H., Price, B. H., Nierenberg, A. A., Jenike, M. A., & Rauch, S. L. (2002). Prospective long-term follow-up of 44 patients who received cingulotomy for treatment-refractory obsessive-compulsive disorder. *American Journal of Psychiatry, 159*(2), 269-275.

Dumont, R. (1997). *The sky is falling*. New York: W. N. Norton.

Eddy, M. F., & Walbroehl, G. S. (1998). Recognition and treatment of obsessive-compulsive disorder. *American Family Physician, 57*(7), 1623-1628.

Eisen, J. L., Goodman, W. K., Keller, M. B., Warshaw, M. G., DeMarco, L. M., Luce, D. D., et al. (1999). Patterns of remission and relapse in obsessive-compulsive disorder: A 2-year prospective study. *Journal of Clinical Psychiatry, 60*(5), 346-351.

Enright, S. (1991). Group treatment for obsessive-compulsive disorder: An evaluation. *Behavioural Psychotherapy, 19*, 183-192.

Erickson, E. (1950). *Childhood and society*. New York: Norton.

Fals-Stewart, W., & Lucente, S. (1994). Behavioural group therapy with obsessive-compulsives: An overview. *International Journal of Group Psychotherapy, 44*(1), 35-51.

Fals-Stewart, W., Marks, A., & Schafer, J. (1993). A comparison of behavioural group therapy and individual behaviour therapy in treating obsessive-compulsive disorder. *Journal of Nervous and Mental Disease, 181*(3), 189-193.

Fineberg, N. A., O'Doherty, C., Rajagopal, S., Reddy, K., Banks, A., & Gale, T. (2003). How common is obsessive compulsive disorder in a dermatology outpatient clinic? *Journal of Clinical Psychiatry, 64*(2), 152-155.

Flament, M., & Bisserbe, J. C. (1997). Pharmacologic treatment of obsessive-compulsive disorder: Comparative studies. *Journal of Clinical Psychiatry, 58*(Suppl. 12), 18-22.

Flament, M., Whitaker, A., Rapoport, J., Davies, M., Berg, C., Kalikow, K., et al. (1988). Obsessive compulsive disorder in adolescence: An epidemiological study. *American Academy of Child and Adolescent Psychiatry, 27*(6), 764-771.

Fowler, M. D. (1988). Ethical issues in nursing research: Issues in qualitative research. *Western Journal of Nursing Research, 10*(1), 109-111.

Francobandiera, G. (2002). Quetiapine augmentation of sertraline in obsessive compulsive disorder. *Journal of Clinical Psychiatry, 63*(11), 1004-1009.

Frank, A. (1995). *The wounded storyteller.* Chicago: University of Chicago Press.

Franklin, M. E., Abramowitz, J. S., Bux, D. A., Zoellner, L. A., & Feeny, N. C. (2002). Cognitive-behavioural therapy with and without medication in the treatment of obsessive-compulsive disorder. *Professional Psychology-Research & Practice, 33*(2), 162-1168.

Franzblau, S. A. (1997). The phenomenology of ritualized and repeated behaviours in nonclinical populations in the United States. *Cultural Diversity and Mental Health, 3*(4), 259-272.

Freud, S. (1973). *Three case histories*. (P. Rieff, Trans.). New York: Macmillan. (Original work published 1814)

Gabriels, L., Cosyns, P., Nuttin, B., Demeulemeester, H., & Gybels, J. (2003). Deep brain stimulation for treatment-refractory obsessive-compulsive disorder: Psychopathological and neuropsychological outcome in three cases. *Acta Psychiatrica Scandinavica, 107*(4), 275-282.

Glazer, M. (1980, October). The threat of the stranger. *Hastings Center Report,* pp. 25-31.

Gold-Steinberg, S., & Logan, D. (1999). Integrating play therapy in the treatment of children with obsessive-compulsive disorder. *American Journal of Orthopsychiatry, 69*(4), 495-503.

Goodwin, D. W., Guze, S. B., & Robins, E. (1969). Follow-up studies in obsessional neurosis. *Archives of General Psychiatry, 20*, 182-187.

Goodwin, R., Koenen, K. C., Hellman, F., Guardino, M., & Struening, E. (2002). Helpseeking and access to mental health treatment for obsessive compulsive disorder. *Acta Psychiatrica Scandinavica, 106*(2), 143-149.

Gravitz, H. L. (1998). *Obsessive compulsive disorder: New help for the family*. Santa Barbara, CA: Healing Vision Press.

Grayson, J., & Frankel, G. (1995). Strange bedfellows: OCD and camping. *Journal of the California Alliance for the Mentally Ill, 6*(1), 41-43.

Greist, J. H. (1990). Treatment of obsessive compulsive disorder: Psychotherapies, drugs, and other somatic treatments. *Journal of Clinical Psychiatry, 51*(Suppl. 8), 44-50.

Greist, J. H. (1996). New developments in behaviour therapy for obsessive-compulsive disorder. *International Clinical Psychopharmacology, 11*(Suppl. 5), 63-73.

Greist, J. H., & Jefferson, J. (1998). Pharmacotherapy for obsessive-compulsive disorder. *British Journal of Psychiatry, 173*(Suppl. 35), 64-70.

Greist, J. H., Marks, I. M., Baer, L., Kobak, K. A., Wenzel, K. W., Hirsch, M. J., Mantle, J. M., & Clary, C. M. (2002). Behavior therapy for obsessive-compulsive disorder guided by a computer or by a clinician compared with relaxation as a control. *Journal of Clinical Psychiatry, 63*(2), 138-145.

Grimm, S. (1995). Parenting a child with OCD. *Journal of the California Alliance for the Mentally Ill, 6*(1), 19-21.

Haase, M. (1998). A mother's story of obsessive compulsive disorder. *Partners in Psychiatric Health Care, 1*(1), 5-9.

Haase, M. (2002). Living with obsessive compulsive disorder. In M. van Manen (Ed.), *Writing in the dark* (pp. 61-83). London, ON: Althouse.

Hand, I. (1998). Out-patient, multi-modal behaviour therapy for obsessive-compulsive disorder. *British Journal of Psychiatry, 173*(Suppl. 35), 45-52.

Hanna, G. (1995). Demographic and clinical feature of obsessive compulsive disorder in children and adolescents. *Journal of American Academy of Child and Adolescent Psychiatry, 34*(1), 19-27.

Hayne, Y., & Yonge, O. (1997). The lifeworld of the chronic mentally ill: Analysis of 40 written personal accounts. *Archives of Psychiatric Nursing, 11,* 314-324.

Hillbom, E. (1960). After-effects of brain injuries. *Acta Psychiatr Neurol Scand, 35*(Suppl. 142).

Hoad, T. F. (Ed.). (1986). *Oxford concise dictionary of English etymology.* Oxford: Oxford University Press.

Hollander, E., Bienstock, C. A., Koran, L. M., Pallanti, S., Marazitti, D., Rasmussen, S. A., Ravizza, L., Benkelfat, C., Saxena, S., Greenberg, B. D., Sasson, Y. & Zohar, J. (2002). Refractory obsessive-compulsive disorder: State-of-the-art treatment. *Journal of Clinical Psychiatry, 63*(Suppl. 6), 20-29.

Hollander, E., Jenike, M., & Shahady, E. J. (1996). Help for hands that can't stop washing. *Patient Care, 30*(11), 66-68, 73-80, 85.

Hollander, E., Kwon, J., Stein, D., Broatch, J., Rowland, C., & Himelein, C. (1996). Obsessive compulsive and spectrum disorders: Overview and quality of life issues. *Journal of Clinical Psychiatry, 57*(Suppl. 8), 3-6.

Hollander, E., Stein, D., Broatch, J., et al. (1995, December). A pharmaco-economic and quality of life study of OCD. In *Scientific abstracts of the 34th annual meeting of the American College of Neuropsychopharmacology*, San Juan, Puerto Rico.

Holloway, I., & Wheeler, S. (1995). Ethical issues in qualitative nursing research. *Nursing Ethics, 2*(3), 223-232.

Hull, M. (1995). Learning to live with myself and my OCD. *Journal of the California Alliance for the Mentally Ill, 6*(1), 25-27.

Hunter, R., & Macalpine, I. (1963). *Three hundred years of psychiatry*. London: Oxford University Press.

Hurley, R. A., Saxena, S., Rauch, S. L., Hoehn-Saric, R., & Taber, H. K. (2002). Predicting treatment response in obsessive compulsive disorder. *Journal of Neuropsychiatry & Clinical Neurosciences, 14*(3), 249-253.

Inglis, R. B., Stauffer, D. A., & Larsen, C. (Eds.). (1952). *Adventures in English literature*. Ottawa: Gage.

Jackson, B. S. (1993). Hope and wound healing. *Journal of ET Nursing, 22*(2), 73-77.

Jenike, M. A. (1989). Obsessive compulsive and related disorders: A hidden epidemic. *New England Journal of Medicine, 321*, 539-541.

Jenike, M. A. (1998a). Neurosurgical treatment of obsessive-compulsive disorder. *British Journal of Psychiatry, 173*(Suppl. 35), 79-90.

Jenike, M. A. (1998b). Theories of etiology. In M. A. Jenike, L. Baer, & W. E. Minichiello (Eds), *Obsessive-compulsive disorders: Practical management* (3rd ed.; pp. 203-221). Toronto: Mosby.

Jenike, M. A., & Brandon, A. D. (1988). Obsessive-compulsive disorder and head trauma: A rare association. *Journal of Anxiety Disorders, 2*, 353-359.

Jenike, M., Baer. L., & Minichiello, W. (1998). An overview of obsessive-compulsive disorder. In M. A. Jenike, L. Baer, & W. E. Minichiello (Eds)., *Obsessive-compulsive disorders: Practical management* (pp. 3-11). Toronto: Mosby.

Johnson, S. (1960). Samuel Johnson. In *The Encyclopedia Britannica* (Vol. 13, pp. 108-116). Toronto: Encyclopedia Britannica.

Kampman, M., Keijsers, G. P. J., Hoogduin, C. A. L., & Verbraak, M. J. P. M. (2002). Addition of cognitive behaviour therapy for obsessive compulsive disorder patients non-responding to fluoxetine. *Acta Psychiatrica Scandinavica, 106*(4), 314-319.

Karistianis, G. (2003). Orienting attention in obsessive compulsive disorder. *Cognitive & Behavioral Neurology, 16(1), 68-74.*

Karno, M., Golding, J., Sorenson, S., & Burnom, A. (1988). The epidemiology of OCD in five US communities. *Archives of General Psychiatry, 45*, 1094-1099.

Keats, J. (1904). To sleep. In *The Bibliophile Library of Literature Art and Rare Manuscripts* (Vol. 4, p. 1410). New York: International Bibliophile Society.

King, N., Ollendick, T., & Montgomery, I. (1995). Obsessive compulsive disorder in children and adolescents. *Behaviour Change, 12*(1), 51-58.

Kirkby, K. C. (2003). Obsessive compulsive disorder: Towards better understanding and outcomes. *Current Opinions in Psychiatry, 16*(1), 49-55.

Klein, E. (1971). *A comprehensive etymological dictionary of the English language.* New York: Elsevier.

Kolada, J. L., Bland, R. C., & Newman, S. C. (1994). Obsessive compulsive disorder. *Acta Psychiatrica Scandinavica* (Suppl. 376), 24-35.

Kozak, M., & Foa, E. (1994). Obsessions, overvalued ideas, and delusions in obsessive compulsive disorder. *Behaviour, Research, and Therapy, 32*(3), 343-353.

Kringlen, E. (1965). Obsessional neurotics: A long-term follow-up. *British Journal of Psychiatry, 111*, 709-722.

Ladouceur, R., Freeston, M., & Gagnon, F. (1996). Obsessive compulsive disorder: Diagnosis and management. *Canadian Family Physician, 42*, 1169-1178.

Lazarus, R. S. (1982). Thoughts on the relations between emotion and cognition. *American Psychologist, 37*(9), 1019-1024.

Lazarus, R. S. (1991). Cognition and motivation in emotion. *American Psychologist, 46*(4), 352-367.

Lazarus, R. S. (1995). Cognition and emotion from the RET viewpoint. *Journal of Rational-Emotive & Cognitive-Behaviour Therapy, 13*(1), 29-54.

Leininger, M. M. (1985). *Qualitative research methods in nursing.* New York: Grune & Stratton.

Levinas, E. (1985). *Ethics & Infinity.* Pittsburgh: Duquesne University Press.

Levine, R. J. (1986). *Ethics and regulation of clinical research* (2nd ed.). Baltimore: Urban.

Lewis, A. (1971). The ambiguous word "anxiety." *International Journal of Psychiatry, 9*, 62-110.

Liebowitz, M. (1998). Anxiety disorders and obsessive compulsive disorder. *Neuropsychobiology, 37*, 69-71.

Lindsay, M., Crino, R., & Andrews, G. (1997). Controlled trial of exposure and response prevention in obsessive compulsive disorder. *British Journal of Psychiatry, 171*, 135-139.

Linschoten, C. J. (1952). "Over het inslapen." *Tijdschrift v. Philosophie, 14*, 207-264.

Lishman, W. A. (1968). Brain damage in relation to psychiatric disability after head injury. *British Journal of Psychiatry, 114*, 373-410.

Marieb, E. N. (1989). *Human anatomy and physiology.* Redwood City, CA: Benjamin/Cummings.

Marks, I. (1997). Behaviour therapy for obsessive-compulsive disorder: A decade of progress. *Canadian Journal of Psychiatry, 42*, 1021-1027.

Mataix-Cols, D., Rauch, S. L., Baer, L., Eisen, J. L., Shera, D. M., Goodman, W., K., Rasmussen, S. S., & Jenike, M. A. (2002). Symptom stability in adult obsessive-compulsive disorder: Data from a naturalistic two-year follow-up study. *American Journal of Psychiatry, 159*(2), 263-268.

McCormick, M. (1993). New hope for patients with obsessive compulsive disorders. *Journal of the American Academy of Physician Assistants, 6*, 283-290.

McKay, D. (1997). A maintenance program for obsessive-compulsive disorder using exposure with response prevention: 2-year follow-up. *Behaviour Research, and Therapy, 35*(4), 367-369.

Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans.). New York: Routledge. (original work published 1945)

Meyer, V. (1966). Modification of expectations in cases with obsessional rituals. *Behaviour Research and Therapy, 4*, 273-280.

Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.

Mnuchin, V., & Hollander, E. (1995). Isabel. *Journal of the California Alliance for the Mentally Ill, 6*(1), 14-16.

Monte, C. F. (1995). *Beneath the mask: An introduction to theories of personality* (5th ed.). Fort Worth, TX: Harcourt Brace.

Morse, J. M. (Ed.). (1992). *Qualitative health research*. Newbury Park, CA: Sage.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.

Munhall, P. (1989). Philosophical ponderings on qualitative research methods in nursing. *Nursing Science Quarterly, 2*(1), 20-28.

Munhall, P. (1991). Institutional review of qualitative research proposals: A task of no small consequence. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 258-271). London, ON: Sage.

Muris, P., Merckelbach, H., & Clavan, M. (1997). Abnormal and normal compulsions. *Behaviour Research and Therapy, 35*(3), 249-252.

Nemiah, J. C. (1967). Psychoneurotic disorders: Obsessive-compulsive and neurotic depressive reactions. In A. M. Freedman & H. I. Kaplan (Eds.), *Comprehensive textbook of psychiatry* (pp. 912-928). Baltimore: Williams & Wilkins.

Newman, S. C., & Bland, R. C. (1998). Incidence of mental disorders in Edmonton: Estimates of rates and methodological issues. *Journal of Psychiatric Research, 32*(5), 273-282.

Noyes, R., & Hoehn-Saric, R. (1998). *The anxiety disorders.* Cambridge: University Press.

O'Connor, K., Todorov, C., Robillard, S., Borgeat, F., & Brault, M. (1999). Cognitive-behaviour therapy and medication in the treatment of obsessive-compulsive disorder: A controlled study. *Canadian Journal of Psychiatry, 44*, 64-71.

Olofsson, B., Gilje, F., Jacobsson, L., & Norberg, A. (1998). Nurses' narratives about using coercion in psychiatric care. *Journal of Advanced Nursing, 28*(1), 45-53.

O'Neill, S. (1999). Living with obsessive-compulsive disorder: A case study of a woman's construction of self. *Counseling Psychology Quarterly, 12*(1), 73-86.

Overbeek, T., Schruers, K., Vermetten, E., & Griez, E. (2003). Comorbidity of obsessive compulsive disorder and depression: Prevalence, symptom severity, and treatment effect. *Journal of Clinical Psychiatry, 63*(12), 1106-1112.

Parker, W. C. (1984). Interviewing children: Problems and promise. *Journal of Negro Education, 53*(11), 18-28.

Perugi, G., Toni, C., Frare, F., Travierso, M. C., Hantouche, E., & Akiskal, H. S. (2003). Obsessive compulsive-bipolar comorbidity: A systematic exploration of clinical features and treatment outcome. *Journal of Clinical Psychiatry, 63*(12), 1129-1134.

Phillips, K. A. (2002). The obsessive compulsive spectrums. *Psychiatric Clinics of North America, 25*(4), 791-809.

Pigott, T. (1996). OCD: Where the serotonin selectivity story begins. *Journal of Clinical Psychiatry, 57*(Suppl. 6), 11-20.

Pigott, T. A., & Seay, S. M. (1999). A review of the efficacy of selective serotonin reuptake inhibitors in obsessive-compulsive disorder. *Journal of Clinical Psychiatry, 60*(2), 101-106.

Price, L. H., Rasmussen, S. A., & Eisen, J. (1999). The natural history of obsessive-compulsive disorder. *Archives of General Psychiatry, 56*, 131-132.

Purdon, C., & Clark, D. A. (1994). Obsessive intrusive thoughts in nonclinical subjects. Part II. Cognitive appraisal, emotional response and thought control strategies. *Behaviour Research and Therapy, 32*(4), 403-410.

Rachman, S., & De Silva, P. (1978). Abnormal and normal obsessions. *Behaviour Research and Therapy, 16*, 233-248.

Rachman, S., & Hodgson, R. (1980). *Obsessions and compulsions*. Englewood Cliffs, NJ: Prentice Hall.

Ramos, M. C. (1989). Some ethical implications of qualitative research. *Research in Nursing & Health, 12*, 57-63.

Rapoport, J. (1989a). The biology of obsessions and compulsions. *Scientific America* (March), 83-89.

Rapoport, J. (1989b). *The boy who couldn't stop washing*. New York: Dutton.

Rapoport, J. (1990). The waking nightmare: An overview of obsessive compulsive disorder. *Journal of Clinical Psychiatry, 51*(11), 25-28.

Rapoport, J., & Baer, L. (1993). Obsessive compulsive disorder in children and adolescents: Issues in management. *Journal of Clinical Psychiatry, 54*(Suppl. 6), 30.

Rapoport, J., Leonard, H., Swedo, S., & Lenane, M. (1993). Obsessive compulsive disorder in children and adolescents: Issues in management. *Journal of Clinical Psychiatry, 54*(Suppl. 6), 27-29.

Rapoport, J., Swedo, S., & Leonard, H. (1992). Childhood obsessive compulsive disorder. *Journal of Clinical Psychiatry, 53*(Suppl. 4), 11-16.

Rasmussen, S. A., & Eisen, J. L. (1998). The epidemiology and clinical features of obsessive-compulsive disorder. In M. A. Jenike, L. Baer, & W. E. Minichiello (Eds), *Obsessive-compulsive disorders: Practical management* (3rd ed.; pp. 12-43). Toronto: Mosby.

Rasmussen, S., & Eisen, J. (1992). The epidemiology and differential diagnosis of obsessive compulsive disorder. *Journal of Clinical Psychiatry, 53*(Suppl. 4), 4-10.

Rasmussen, S., & Eisen, J. (1997). Treatment strategies for chronic and refractory obsessive-compulsive disorder. *Journal of Clinical Psychiatry, 58*(Suppl. 13), 9-13.

Raudonis, B. (1992). Ethical considerations in qualitative research with hospice patients. *Qualitative Health Research, 2*(2), 238-249.

Renshaw, K. D., Chambless, D. L., Steketee, G. (2003). Perceived criticism predicts severity of anxiety symptoms after behavioral treatment in patients with obsessive compulsive disorder and panic disorder with agoraphobia. *Journal of Clinical Psychology, 59*(4), 411-421.

Rettew, D., Swedo, S., Leonard, H., Lenane, M., & Rapoport, J. (1992). Obsessions and compulsion across time in 79 children and adolescents with obsessive compulsive disorder. *Journal of American Academy of Child and Adolescent Psychiatry, 31*(6), 1050-1056.

Rheaume, J., Ladouceur, R., Freeston, M., & Letarte, H. (1995). Inflated responsibility in obsessive compulsive disorder: Validation of an operational definition. *Behaviour Research and Therapy, 33*(2), 159-169.

Rothenberg, A. (1998). Diagnosis of obsessive-compulsive illness. *The Psychiatric Clinics of North America, 21*(4), 791-801.

Rotzer, F. (1995). *Conversations with French philosophers* (G. E. Aylesworth, Trans.). Atlantic Highlands, NJ: Humanities Press.

Salkovskis, P. (1985). Obsessional-compulsive problems: A cognitive-behavioural analysis. *Behaviour Research and Therapy, 23*(5), 571-583.

Salkovskis, P. M., & Campbell, P. (1994). Thought suppression induces intrusion in naturally occurring negative intrusive thoughts. *Behaviour Research and Therapy, 32*(1), 1-8.

Salkovskis, P., Forrester, E., & Richards, C. (1998). Cognitive-behavioural approach to understanding obsessional thinking. *British Journal of Psychiatry, 173*(Suppl. 35), 53-63.

Salkovskis, P., Westbrook, D., Davis, J., Jeavons, A., & Gledhill, A. (1997). Effects of neutralizing on intrusive thoughts: An experiment investigating the etiology of obsessive-compulsive disorder. *Behaviour Research and Therapy, 35*(3), 211-219.

Sartre, J.-P. (1956). *Being and nothingness: The principal text of modern existentialism* (H. E. Barnes, Trans.). Toronto: Washington Square Press. (Original work published 1943)

Sasson, Y., Zohar, J., Chopra, M., Lustig, M., Iancu, I., & Hendler, T. (1997). Epidemiology of obsessive-compulsive disorder: A world view. *Journal of Clinical Psychiatry, 58*(Suppl. 12), 7-10.

Saxena, S., Maidment, K. M., Vapnik, T., Golden, G., Rishwain, T., Rosen, R. M., Tarlow, G., & Bystritsky, A. (2002). Obsessive-compulsive hoarding: Symptom severity and response to multimodal treatment. *Journal of Clinical Psychiatry, 63*(1), 21-27.

Schwartz, J. (1996). *Brain lock*. New York: Regan.

Schwartz, J. (1998). Neuroanatomical aspects of cognitive-behavioural therapy response in obsessive-compulsive disorder. *British Journal of Psychiatry, 173*(Suppl. 35), 38-44.

Selye, H. (1974). *Stress without distress*. Philadelphia: Lippincott.

Skoog, G., & Skoog, I. (1999). A 40-year follow-up of patients with obsessive-compulsive disorder. *Archives of General Psychiatry, 56*(2), 121-127.

Spitzer, M., & Sigmund, D. (1997). The phenomenology of obsessive-compulsive disorder. *International Review of Psychiatry, 9*, 7-13.

Stake, R. (1995). *The art of case study research*. Thousand Oaks, CA: Sage.

Steketee, G., & Pruyn, N. (1998). In R. P. Swinson, M. M. Antony, S. Rachman, & M. A. Richter (Eds.), *Obsessive-compulsive disorder: Theory, research, and treatment* (pp. 120-140). New York: Guilford Press.

Steketee, G., Frost, R., & Cohen, I. (1998). Beliefs in obsessive-compulsive disorder. *Journal of Anxiety Disorders, 12*(6), 525-537.

Steketee, G., Frost, R., Rheaume, J., & Wilhelm, S. (1998). In M. A. Jenike, L. Baer, & W. Minichiello (Eds.), *Obsessive-compulsive disorders: Practical management* (3rd ed.; pp. 368-399). New York: Mosby.

Steketee, G., Grayson, J. B., & Foa, E. B. (1985). Obsessive-compulsive disorder: Differences between washers and checkers. *Behaviour Research and Therapy, 23*, 197-201.

Susin, J. (1997). Exchanging one illness for another. *Journal of the California Alliance for the Mentally Ill, 8*(3), 27-28.

Swanson-Kauffman, K., & Schonwald, E. (1988). Phenomenology. In B. Sarter (Ed.), *Paths to knowledge: Innovative research methods for nursing* (pp. 97-105). New York: National League for Nursing.

Thompson, D. (1995). *The concise Oxford dictionary of current English* (9th ed.). Oxford: Clarendon Press.

Thomsen, P. H. (1996). Treatment of obsessive compulsive disorder in children and adolescents: A review of the literature. *European Child & Adolescent Psychiatry, 5*(2), 55-66.

Toro, H., Cervera, M., Osejo, E., & Salamero, M. (1992). Obsessive compulsive disorder in childhood and adolescence: A clinical study. *Journal of Child Psychology and Psychiatry, 33*(6), 1025-1037.

Usher, K., & Holmes, C. (1997). Ethical aspects of phenomenological research with mentally ill people. *Nursing Ethics, 4*(1), 49-56.

Valleni-Basile, L., Garrison, C., Jackson, K., Waller, J., McKeown, R., Addy, C., et al. (1994). Frequency of obsessive compulsive disorder in a community sample of young adolescents. *Journal of American Academy of Child and Adolescent Psychiatry, 33*(6), 782-791.

van Balkom, A., van Oppen, P., Vermeulen, A., van Dyck, R., Nauta, M., & Vorst, H. (1994). A meta-analysis on the treatment of obsessive compulsive disorder: A comparison of antidepressants, behaviour, and cognitive therapy. *Clinical Psychology Review, 14*, 359-381.

van den Berg, J. H. (1966). *The psychology of the sickbed*. Pittsburgh: Duquesne University Press.

van den Berg, J. H. (1972). *A different existence: Principles of phenomenological psychopathology*. Pittsburgh: Duquesne University Press.

van Manen, M. (2002). Care-as-worry, or "don't worry be happy." *Qualitative Health Research: An International, Interdisciplinary Journal. 12*(2), 264-280.

van Manen, M. (1997). *Researching lived experience.* London, ON: Althouse.

van Oppen, P., & Arntz, A. (1994). Cognitive therapy for obsessive-compulsive disorder. *Behaviour Research and Therapy, 32*(1), 79-87.

van Oppen, P., De Haan, E., van Balkom, A., Spinhoven, P., Hoogduin, K., & van Dyck, R. (1995). Cognitive therapy and exposure in vivo in the treatment of obsessive compulsive disorder. *Behaviour Research and Therapy, 33*(4), 379-390.

Vellenga, B., & Christenson, J. (1994). Persistent and severely mentally ill clients' perceptions of their mental illness. *Issues in Mental Health Nursing, 15*, 359-371.

Wang, C. H. Knowing and approaching hope as human experience: Implications for the medical-surgical nurse. *Medsurg Nursing, 9*(4), 189-192.

Warneke, L. (1993). Anxiety disorders: Focus on obsessive compulsive disorder. *Canadian Family Physician, 39*(7), 1612-1621.

Warneke, L. (1996). OCD: Get rid of the rituals. *Medicine North America* (April), 49-57.

Warnock, J., & Kestenbaum, T. (1996). Obsessive compulsive disorder. *Psychodermatology, 13*(3), 465-472.

Watson, A. B. (1982). Informed consent of special subjects. *Nursing Research, 31*(1), 43-47.

Weissman, M. M., Bland, R. C., Canino, G. J. Greenwald, S., Hwu, H. G., Lee, C. K., et al. (1994). The cross national epidemiology of obsessive-compulsive disorder. *Journal of Clinical Psychiatry, 55*(Suppl. 3). 5-10.

Welton, D. (1999). Introduction: Foundations of a theory of the body. In D. Welton (Ed.), *The body* (pp. 1-8). Oxford: Blackwell.

Westphahl, G. (1878). Uber Swangsvorstellungen. *Archiv fur Psychiatra und Nervenkrankheiten, 8*, 734-750.

Wilson, K., & Chambless, D. (1999). Inflated perceptions of responsibility and obsessive-compulsive symptoms. *Behaviour Research and Therapy, 37*, 325-335.

Wright, M., & Hewlett, W. (1994). Neurobilolgy of obsessive compulsive disorder. *Comprehensive Therapy, 20*(2), 95-100.

Yaryura-Tobias, J. A., & Bhagavan, H. N. (1977). L-tryptophan in obsessive-compulsive neurosis. *American Journal of Psychiatry, 134*, 1298-1299.

Yaryura-Tobias, J. A., Todaro, J., Grunes, M. S., McKay, D., Stockman, R., & Neziroglu, F. (1996). *Comorbidity versus continuum of axis 1 disorders in OCD*. Paper presented at the meeting of the Association for Advancement of Behaviour Therapy, New York.

Yonge, O., & Stewin, L. (1988). Reliability & validity: Misnomers for qualitative research. *The Canadian Journal of Nursing Research, 20*(2), 61-67.

Zetin, M., & Kramer, M. (1992). Obsessive compulsive disorder. *Hospital and Community Psychiatry, 43*(7), 689-697.

Zohar, A. H., Ratzoni, G., Pauls, D. L., Apter, A., Bleich, A., Kron, S., et al. (1992). An epidemiological study of obsessive compulsive disorder and related disorders in Israeli adolescents. *Journal of American Academy of Child and Adolescent Psychiatry, 31*(6), 1057-1061.

Zohar, J., Insel, T., & Rasmussen, S. (Eds.). (1991). *The psychobiology of obsessive-compulsive disorder*. New York: Springer.

APPENDIX A

DSM IV DIAGNOSTIC CRITERIA

Diagnostic criteria for 300.3 Obsessive-Compulsive Disorder

A. Either obsessions or compulsions:
Obsessions as defined by (1), (2), (3), and (4):
(1) recurrent and persistent thoughts, impulses, or images that are experienced, at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress
(2) the thoughts, impulses, or images are not simply excessive worries about real-life problems
(3) the person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralize them with some other thought or action
(4) the person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion)

Compulsions as defined by (1) and (2)
(1) repetitive behaviours (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly
(2) the behaviours or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviours or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent or are clearly excessive

B. At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable.
Note: This does not apply to children.

C. The obsessions or compulsions cause marked distress, are time consuming (take more than 1 hour a day), or significantly interfere with the person's normal routine, occupational or academic) functioning, or usual social activities or relationships.

D. If another Axis 1 disorder is present, the content of the obsessions or compulsions is not restricted to it (e.g., preoccupation with food in the presence of an Eating Disorder; hair pulling in the presence of Trichotillomania; concern with appearance in the presence of Body Dysmorphic Disorder; preoccupation with drugs in the presence of a Substance Use Disorder; preoccupation with having a serious illness in the presence of Hypochondriasis; preoccupation with sexual urges or fantasies in the presence of a Paraphilia; or guilty ruminations in the presence of Major Depressive Disorder).

E. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition

Specify if:
With Poor Insight: if, for most of the time during the current episode, the person does not recognize that the obsessions and compulsions are excessive or unreasonable

Diagnostic and Statistical Manual of Mental Disorders (1994) p. 422-423.

APPENDIX B

RECRUITMENT ANNOUNCEMENT

Recruitment Announcement

The Lived Experience of Obsessive Compulsive Disorder

Investigator: Mary Haase RN, PhD (c)
University of Alberta
Faculty of Nursing
Phone: (780) 492-9100

Supervisor: Olive Yonge RN, PhD CPsych
University of Alberta
Faculty of Nursing
Phone: (780) 492-2402

WOULD YOU LIKE TO TALK ABOUT YOUR EXPERIECE OF LIVING WITH OBSESSIVE COMPULSIVE DISORDER?

I am a registered nurse who has worked in the area of mental health for 25 years. As a part of my doctoral program, I am conducting an inquiry to explore the meaning of living with obsessive compulsive disorder.

The purpose of this inquiry is to learn more about what it is like to live with obsessive compulsive disorder.

Participants, with obsessive compulsive disorder, who agree to take part in this inquiry, will be invited to engage in informal conversations with myself. There should be no more than three, one hour conversations.

If you would like to hear more about the inquiry before you decide to be involved or if you would like to take part please call me at 492-9100.

APPENDIX C

INFORMATION LETTER

Information Letter

The Lived Experience of Obsessive Compulsive Disorder

Investigator: Mary Haase RN, PhD (c)
University of Alberta
Faculty of Nursing
Phone: (780) 492-9100

Supervisor: Olive Yonge RN, PhD CPsych
University of Alberta
Faculty of Nursing
Phone: (780) 492-2402

The purpose of this inquiry is to gain an understanding of obsessive compulsive disorder (OCD). The information gathered will be used for the researcher's thesis. The research procedure is as follows. You will be asked to consent to the taping of conversations with the researcher. You will be asked to talk to the researcher about your experience with OCD. You may be asked to talk to the researcher more than once. The conversations will each last about one hour. They will take place at a time and place that is convenient to you.

Once the conversation is taped, it will be transcribed. You will be asked to review the transcript. If you wish to, you may make changes to the transcript.

You are free to stop the conversation at any time. You are free to refuse to answer any question. You may withdraw from the inquiry at any time without any threat of penalty. There are no known risks to you. You may not benefit personally from this research, but the information you share may be helpful to other people with OCD or their families. Anonymity and confidentiality will be maintained at all times. Tapes, transcripts, and journals will be kept in a locked cupboard. Only the researcher and her supervisor will have access to them.

Information Letter

The Lived Experience of Obsessive Compulsive Disorder

(Continued)

Investigator: Mary Haase RN, PhD (c)
University of Alberta
Faculty of Nursing
Phone: (780) 492-9100

Supervisor: Olive Yonge RN, PhD CPsych
University of Alberta
Faculty of Nursing
Phone: (780) 492-2402

##########

All information will be held confidential except when professional codes of ethics and/or legislation require reporting.

If you have any concerns about any aspect of this research, you may contact the Patient Concerns Office of the Capital Health Authority at (780) 492-9790. This office has no affiliation with study investigators.

APPENDIX D

INFORMED CONSENT

Informed Consent

Part 1 (to be completed by the Principal Investigator):

Title of Project: The Lived Experience of Obsessive Compulsive Disorder

Principal Investigator: Mary Haase RN, PhD (c), Faculty of Nursing, University of Alberta. Phone: (780) 492-9100

Supervisor: Olive Yonge RN, PhD CPsych, Faculty of Nursing, University of Alberta. Phone: (780) 492-2402

Part 2 (to be completed by the research subject):

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Sheet? Yes No

Do you understand the benefits and risks involved in taking part in this research study? Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care? Yes No

Has the issue of confidentiality been explained to you? Do you understand who will have access to your records? Yes No

Do you want the investigator(s) to inform your family doctor that you are participation in this research study? If so, please provide your doctor's name:_____(N.B. This question is optional). Yes No

This study was explained to me by:_____

I agree to take part in this study.

_____ _____ _____

Signature of Research Participant Date Witness

_____ _____

Printed Name Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ _____

Signature of Investigator Date

APPENDIX E

RESOURCES

Resources

It is very unlikely that the conversations with the researcher will cause you any distress; however, as a precautionary measure resources are available.

If necessary the researcher will assist you in making an appointment with:

1. your family physician
2. your psychiatrist
3. Alberta Mental Health (427-4444)

If necessary the researcher will assist you in making a phone call to:

1. The Support Network (482-4636)
2. Distress Line (482-4357)

APPENDIX F

PERSONNEL

Personnel

Mary Haase, RN, BScN, PhD candidate is the primary investigator for this study. Mary has 25 years experience working in the area of Mental Health Nursing. She has had an interest in obsessive compulsive disorder for many years and has been actively involved with the treatment of obsessive compulsive disorder for about ten years. Mary has co-led several cognitive behavioural group therapy courses and has co led the obsessive compulsive support group in Edmonton. She is well known and trusted by the obsessive compulsive community. Mary has a strong relationship with her supervisor, Olive Yonge.

Olive Yonge, RN, PhD CPsych will be the supervisor of the study. Olive has worked and taught in the area of mental health for 29 years. She has many years of experience using qualitative methods and is very familiar with case study and phenomenology. She has been the primary investigator for numerous qualitative studies. She has agreed to not only supervise the study but to be a mentor to Mary.

A transcriptionist, yet to be hired, will be responsible for the accurate transcription of all audio recorded conversations. The transcriptionist will be aware of the need for confidentiality of all information.

APPENDIX G

DISSEMINATION PLAN

Dissemination Plan

My dissemination plan is outlined below:

Presentations addressing the study will be made to the OCD community and health care professionals; For example, at Margaret Scott Wright Research Day, Canadian Society for Study in Education Conference, and Qualitative Health Research Conference.

Articles addressing the lived experience of OCD will be submitted for publication in nursing journals such as *Archives of Psychiatric Nursing, Journal of Advanced Nursing, and Qualitative Health Research.*

An article will be written for a magazine such as *Chatelaine.*

A support group for individuals with OCD and their families will be reformed in the Edmonton area.

If resources permit:

a. A book will be written for individuals with OCD and for health care professionals.

b. A web site will be constructed for consumer access.

c. Determination of government agencies will be made to facilitate establishment of a telephone help line for consumers.

d. An information pamphlet will be written for persons with OCD and their families.

e. A video will be produced for health care teaching of nursing students and staff.